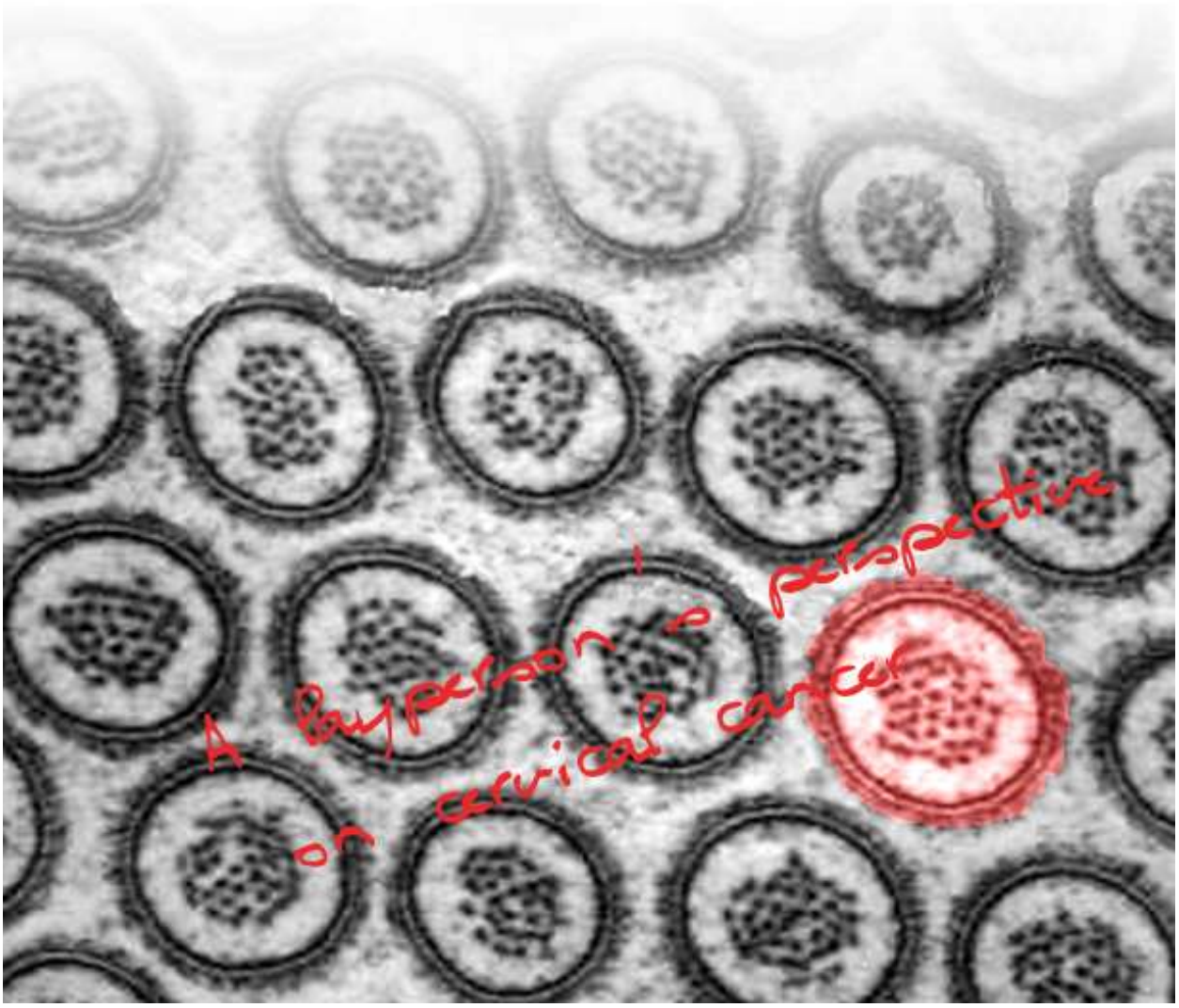
The Cost of not Knowing:

By Ian and Belle Malcomson



THE COST OF NOT KNOWING:

A LAYPERSON'S PERSPECTIVE ON CERVICAL CANCER

By Ian and Belle Malcomson

We know that the whole creation has been groaning as in the pains of childbirth right up to the present time.

Romans 8 v. 22 (NIV)

The argument was willful,
The alternatives untrue,
We need no metaphysics
To sanction what we do
Or to muffle us in comfort
From what we did not do.

Louis MacNeice, London Rain

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Family and Personal Background 2003

A. Ian Malcomson:
   - Birthplace: Northern Ireland.
   - Arrival in Canada: l954.
   - Education: B. Ed. (secondary) and M. A.
   - Occupation: Public school system - 25+ years.
   - Political affiliations: Voted for right of center party.
   - Hobbies and personal interests: Extensive reading of government, history, and contemporary literature, writing, gardening, foreign movies, golfing and jogging.

B. Belle Malcomson:
   - Birthplace: Northern Ireland.
   - Arrival in Canada: 1978.
   - Education: High school graduation with extensive financial training through business school and college.
   - Occupation: Home
   - Hobbies and personal interests: Reading, gardening, computers, dressmaking and exercising.

C. Family:
   - Peter (studying to be an accountant).
   - Eliot (studying to be a computer animator).

D. Favorite Past Times as a Family:
   - Travel: Western & Eastern USA, Australia, Ireland, Western Europe, Eastern Canada, Hawaii.
   - Investigating second-hand bookstores.
   - Watching foreign movies.
   - Hiking.
   - Visiting museums and galleries.

E. Favorite Foods:
   - Golden potatoes and baked ham.
   - Antipasto and crackers.
   - Turkey and lentil soup.
   - Homemade fish and chips.
   - Swedish meatballs.
   - Homemade cheesecake.
   - Rhubarb crisp.
   - Chili.
   - Spaghetti.
   - Caramel squares.
   - Black Forest cakes.

F. Extent of Knowledge:
   - Wide use of computers.
   - Around 6,000 books in home library.
   - Limited knowledge about mechanical things.
   - Absolutely no effective knowledge about cancer until this past year!

Foreword

The big temptation in writing an autobiographical account of the past few years of our lives is to overstate Belle's case by embellishing the facts and telling all so that we can catch people's attention and win their approval. Such a strategy, while not new to the world of writing, has many potential pitfalls. One, readers may see the vivid and intense descriptions as nothing more than an attempt to create a story where one doesn't exist. Two, the true purpose of writing the book becomes mistaken for something else such as making money or becoming famous.

For us, there is no fantastic picture that emerges from this book. While some of the moments here may appear to be incredible and slightly bizarre, they are only a part of our efforts to make sense of a large slew of events that surrounded Belle's illness. We have applied the first rule of historical analysis in all our writing: work with what we have and don't embroider it to fit some preconceived notion of what it might have been like. In the order of things, the story comes first, the analysis next and the all-important conclusions last.

In the narrative - Part One - every pertinent detail encompassing the discovery of the disease, its treatment and recovery is laid on the line. It was during this period that we, as a family, came to grips, like countless other families, with a real crisis. We learned to cope, trust, pray, assist others and even help ourselves solve the mystery behind Belle's cancer. Serious medical sleuthing in search of the imponderable is an essential part of the research found in this book. Not for one moment did we believe that Belle contracted cancer by accident or personal neglect.

The follow-up analysis in Part Two looks at a more technical side of the subject of cervical cancer in respect to its etiology and treatment. In this section, we challenge our readers to appreciate the importance of knowing as much as possible about this disease as the best means for preventing or curing it. For us, the key issue comes down to the way in which Belle's Pap smears were handled. Not surprisingly, these chapters contained the greatest number of footnotes in recognition of some very respected authorities in the field of gynecological cancer.

The following conclusions came as a result of what we learned in those twenty-four months:

A. Many cancers, including cervical, are curable if caught early.
B. Cancer has the potential to destroy and alter lives irrevocably.
C. Many forms of cancer (including cervical) are very hard to diagnose because there are no symptoms at the beginning or are readily mistaken for something else. One symptom by itself is usually not grounds for concern. In Belle's case, it should have been.
D. Cancer is an irregular cell growth caused by an oncogene (foreign virus) invading the DNA of a healthy cell and taking over its reproductive system.
E. Cancer treatment is best pursued through conventional means. Most alternative means should be left as a last resort.
F. Doctors, like the rest of us, are only human. In Belle's case, they provided a lousy diagnosis while facilitating a near miraculous cure.
G. The medical system for this country needs more doctors who care for their patients, more politicians who are aware of where the real needs are and people who are more proactive in taking care of their own health needs.
H. The last few years have taught us to appreciate our health as something worth preserving. This might mean making sure that the quality of healthcare never becomes slipshod to the point of jeopardizing the health of the individual.

PART ONE

Our Story

There is a time for everything and a season for every activity under heaven.

Ecclesiastes 3 v. 1

Chapter 1

A Time of Discovery

1. A Day in March

March 24, l999, has become a red-letter date for all the members of our immediate family. What was about to happen would impact our collective and individual lives in a very transforming way. This became both a collective and personal moment when we would begin to learn that attitude without character is not credible in times of crisis.

I had just arrived home late from work when my wife, Belle, mentioned casually that she had gone to see the doctor that afternoon about a lump on her right groin. The doctor had done an internal examination and, without any explanation, said that she would set up an appointment with a gynecologist in the next city about a hundred twenty miles to the west. There was no sense of concern in Belle's voice as she told me all this. It was, essentially, a referral to a specialist to check out something that might be a problem. There was no need to worry about it until we got the results! The rest of my evening was filled with pestering Belle with all kinds of inane questions about what the doctor had actually discovered; as if that was going to resolve the problem and cancel the needed trip.

The next day, March 25, which was a rather dull and cool morning with very little trace of winter snow on the ground, began like any other day with both Belle and myself getting up around 7:00 a.m. for work. Our two boys are studies in contrast like their parents. Peter, a tall, athletic and handsome l9-year-old accounting student, was up and about and already working on his CGA assignments. On the other hand, Eliot, his younger, witty and sharp 17-year-old brother, of considerably smaller stature, was just beginning to roll into action minutes before taking off for school. The prospect of just another day in the classroom, teaching Canadian and European history to both keen and dull minds, allowed me to briefly forget Belle's concerns. As a public school teacher, of twenty-six years or more, who has even had the privilege of teaching one of his own children in the classroom, I always took my job very seriously. I desired my students to see the bigger picture of life through the lens of history. Understanding the historical context for the problem allows for more accurate appreciation of the situation at hand. This morning was to be no different. I was emotionally charged and ready to teach about the relevance of history to modern times but, yet, I was still bothered by the ever-nagging thought as to why a healthy person like Belle needed an appointment with a gynecologist.

About halfway through the morning, I decided to take the attendance sheets to the office. There, on my mailbox, was a message from Belle asking that I return her call as soon as possible. I had a premonition that we were heading off that day for an all-important appointment with a specialist. Somehow, at that moment, I knew our lives would be changed forever. When I got her on the phone at her office, she calmly told me to pick her up at her school as close to noon as possible to allow us a comfortable two to three hour drive for an afternoon appointment. I can remember the ride as being filled with some small talk and great stretches of silence. This was not unusual because the previous night had rather exhausted any worthwhile speculating as to

what was wrong with Belle. A person does not want to talk much when he is nursing his private fears, trying to put the best face on it and hoping against hope.

Upon arrival at the clinic, we went to see Dr. West on the fifth floor where her office looked out on a majestic range of snow-capped mountains. In the course of an hour, the awful truth came out. It was cervical cancer involving a significantly larger than normal tumor that may have spread to one of the pelvic nodes and manifested itself as a lump on her right groin. Our immediate question, when briefly left by ourselves, was how could this happen when Belle was having regular Pap smear tests and no history of any complications. Knowing that we were in God's care did not lessen the severity and hurt of the moment. The doctor took a biopsy and advised us as to the treatment available if her diagnosis was confirmed within the next few days.

What a hollow feeling as we walked, hand-in-hand, the full length of the local shopping mall after leaving the doctor's office. Total deflation and little inclination to talk to anyone! Instead of being the recipients of information that clarified the problem, we were further in the dark as to how serious Belle's health really was and what we should do next. As much as we would like to believe it, cancer treatment is not as simple as taking a pill, having someone pray over you or having surgery to excise the malignancy.

The trip home that night up the windy highway was filled with intensive discussion as to how to break the news to our sons and friends. It was eventually decided to go ahead and tell some people in our church so that we could get prayer going for Belle's recovery. We are big believers in the power of prayer for anything that concerns us. The biggest and best surprise of that long and, sometimes, torturous day came when Peter and Eliot seemed to calmly take the news in stride and asked what they could do to alleviate the situation. We hoped that this outer composure didn't belie an inner turmoil and uncertainty. After all, they were only young men barely beginning to enjoy life and didn't need to encounter this kind of adversity, or so we thought. Sleep came easily that night because of the sheer exhaustion resulting from the day's events.

2. The Days to Come

The official diagnosis came on the evening of March 29, l999, confirming cervical cancer. Friends were over for business and coffee but the mood of conviviality changed very quickly when the gravity of the situation was grasped. This would be our battle first and foremost. During the next number of days, Belle and I spent considerable time waiting for that phone call that would start the process rolling for treatment. Time was of the essence! The diagnosis had been made so 'let the treatment begin' seemed to be our shared refrain. The window of opportunity to get the provincial cancer agency to look at the problem seemed to be right now. What treatment it would finally recommend was anyone's guess but that didn't matter as long as we got down there fast! We had one of two possible places to go: the two largest cities in the province. A quick phone call ruled out one of them as being available for long-term care because of a serious bed shortage due to an ongoing expansion program. Then there was another anxious call to Belle's gynecologist to confirm that we would take the other one if it were available! Over the next couple of days, we had only the scant assurance that steps would be taken to get Belle admitted as rapidly as possible.

Finally, the date for the major assessment was set for April 12, l999, but we had no guarantee that treatment would begin immediately after the agency had done a risk-assessment. This loose end was proving worrisome for me because I was foreseeing us having to go out of the country for Belle's medical care. Keep in mind that we were not familiar with how the provincial medical system worked in terms of prioritizing patients according to critical needs. Ignorance quite often creates a very hindering paralysis of the mind when it comes to making effective decisions. There was also another pressing matter requiring us to go out of town again to have Belle's pelvic lymph node tested. This we did and the results came back cancerous. Just another date with destiny, popping out of nowhere, and telling us that we were no longer in control of our lives as we once thought. We had no clue as to how to proceed but to do as others more knowledgeable advised us. In our powerless state, we had to buckle down for the ride and prepare for some significant bumps along the way. A strange cue for some of us who saw ourselves as fairly high maintenance people most of our lives.

The uncertainty, confusion and inertia that first hit us gradually left in the ensuing days. There were decisions to be made, plans to be enacted and hurdles to be overcome in a very short period of time if Belle was to recover. There were many kind-hearted people who stepped forward to lend a hand to make the transition as smooth as possible. A lot of prayer was being offered up for Belle's recovery, and we are convinced today that God answered those requests, first and foremost, in granting her eventual recovery.

In times like this, when one's normal life stops and another strange and unwelcome scenario seems to be taking over, it is always advisable to have a network of friends and associates to turn to for help. Belle and I were blessed with invaluable assistance from people at work who understood the enormous pressure and strain we were under to get on with Belle's treatment.

The remaining days before our visit to the cancer agency were spent getting a number of domestic and business matters sorted out. A possible extended absence from home was going to involve taking time off from our jobs, preparing lessons for my supply teacher, writing letters, sending e-mails, visiting friends, instructing our boys on the running of the house, arranging accommodation down south and tidying up unfinished jobs around the house. The week - exhausting as it was - proved invaluable for getting a couple of projects tidied away. We began a herb garden in our newly built greenhouse and consolidated a few loose ends in our home-based business. Over the years, Belle and I have always been committed to finishing off what we've begun. A lot of these challenges proved do-able only because of the kindness of people to intervene and help surmount or circumvent the little and big bureaucratic obstacles. In this modern age, there is no need to struggle and suffer alone. What we didn't know at that time was how meaningful and true that principle was going to be.

When reflecting on those whirligig days, I am truly amazed how Belle's stamina held up under the unrelenting pressure. She stayed on at her job for another week while preparing to host my parents and get things ready for the big move south for extended treatment. If one was seeing Belle for the first time, one might conclude that she was healthy except for a touch of fatigue. Friends were coming to us with well-intended advice on alternative methods for dealing with cancer. Many did not realize the full extent of her illness, and that we would not be willing to pin our hopes on unconventional medicine. While many of the ideas looked interesting they, unfortunately, depended on practices that were untried, unproven and expensive with no definite time frame for a cure.

3. The News Doesn't Get Any Better

There is always that natural feeling that somehow a person's present ordeal or spate of trouble can't go on much longer. We've been programmed to expect our lives to eventually balance itself by fortune and misfortune. After all, isn't that how we develop a good sense of objectivity and personal character in life. There is the hope that everything tends to work itself out in the end! It just so happens that, in the here-and-now, we needed a big dose of faith to see us over the next range of mountains.

For the next two weeks, Belle and I experienced some very frustrating and alarming moments leading up to her eventual treatment. During my annual physical and prostate check-up, our local doctor informed us that he didn't like Belle's chances of getting help at the cancer agency. It was a matter of the system being overworked and not having the resources to handle the Belles of this world. In fact, it was his opinion that the provincial agency had betrayed her by not providing effective monitoring of her Pap smears. All this on top of the fact that she needed critical treatment within the next couple of weeks! Where was the reassurance when we needed it? All we knew was that she had a malignant mass of considerable size in her cervical area, that it had likely metastasized to adjoining parts of her pelvis and could easily spread to other organs if the initiative wasn't seized.

There is only so much a person can pre-occupy himself with before he is forced to return to the looming crisis at hand. Then it hits like the proverbial ton of bricks! One late evening in early April, only a few days away from our visit to the agency, Belle's heavy bleeding, which she had experienced for almost a year by this time, became profuse with passing of great clots of blood. A quick visit to the emergency room at the local hospital to get the problem seen to proved both frustrating and fruitless. Belle's doctor was on call but decided not to check out the symptoms choosing, instead, to dismiss it as just perimenopausal bleeding that could be 'fixed' with wearing large sanitary pads. In hindsight, we can only conclude that he didn't come down to check it out because he wasn't aware of who Belle really was. The modern 'fee for service' medicine doesn't give many doctors a chance to put a name to a face. This rather callous and dismissive treatment was ordered in light of the fact that Belle had just been diagnosed with invasive cervical cancer. If the visit had not been so frustrating, the highlight would have been Belle carrying, out of the hospital, a plastic bag of huge, nappy-like pads to soak up the blood.

Back home, things went from bad to worse in the space of a few hours. By seven o'clock the next morning, Belle was in a state of collapse and too weak to move because of the continuous hemorrhaging. After managing to get her out to the car and back up to emergency, I met the same doctor in the parking lot, and he assisted in wheeling her into the hospital. What was extremely worrying about this whole scene was that Belle was experiencing severe dizziness, palpitations and fainting spells. Four units of blood and a whole day later, Belle was discharged and sent home being most relieved that the immediate problem of low hemoglobin (iron deficiency) had been addressed. It was simply a matter of Belle's accumulative loss of blood over the last year having finally caught up with her. The human body can only afford to lose so much blood and then it goes into a state of shock due, in large part, to the drop in hemoglobin. A drop in hemoglobin had also been a problem a few months earlier when the doctor had prescribed iron tablets to raise it to normal again.

Topping up her blood supply was going to be crucial in determining how successful she was going to be in her cancer treatment. Though we didn't understand the full implications then, this

was going to be an important piece of information in eventually solving the puzzle as to why Belle's cervical cancer went undetected for so long. Conventional wisdom estimates about four to ten years for this kind of cancer to grow. It was likely the exfoliation or peeling away of dead cells from a carcinoma growing on her cervix over this time that caused the heavy bleeding. This, in turn, was taken for menopause and led to a series of questionable Pap smear results. Of course, these were critical facts unknown to us at this time.

During this preliminary time of waiting and preparing, we learned that a good friend from our church, Jane, had contracted what, potentially, looked like some form of abdominal cancer two years after a serious bout of breast cancer. It looked like she was going down south to join Belle at the clinic. What appeared coincidental to begin with turned out very providential in the long run. As we headed into uncharted territory, Jane and her husband were to become an enormous encouragement to us and bring fresh meaning to that biblical quotation that 'a brother is born for adversity'.

There was one unique moment of real discovery that deserves special mention in this overall story. The day came for Belle and I to pull out to go for assessment and possible treatment. As we moved out of the driveway our older boy, Peter, after waving good-bye, stood watching us for a good couple of minutes, perhaps shaken at the fact that we were possibly somehow breaking up as a family. That image of a lonely and solitary figure standing by our house in the cold of that early April morning will stay with us for a lifetime. It became one of those definitive moments when family members learn how important they are to each other. If we could, we would have turned back at that moment and given him another parting hug. Happier, more stable times were to return later to our family after the hardships were endured.

Chapter 2

A Time for the Truth

During the two long days of travel to the agency for treatment, I drove while Belle lay up in the back seat resting. After her recent heavy blood transfusion, her doctor had recommended that she not exert herself in any way. It was strange to be driving over seven hundred miles with my loved one behind and not beside me. Most of the conversation came around to discussing the 'worst case' scenarios and some 'what if' situations. At this time, we had begun reading a number of books on how to fight and overcome cancer. One man we read about had kidney surgery and attended a clinic in Prague for follow-up therapy. During his ordeal, he became convinced that he needed an adjuvant (additional) treatment of enzymes to boost his immune system that had been severely depleted because of surgery. While he did not dismiss conventional treatment as a necessary evil, he did seem to think that it was often advisable to look for complementary forms of medicine to improve recovery.

The hours we spent, during the trip, speculating where we might go if the cancer agency was unable to help Belle raised more questions than answers. Radiation and chemotherapy were processes that only happened to other people, but now they were about to happen to Belle. We had no answers because our basic knowledge of Belle's cancer was very limited. The potential wisdom of experience was absent. We knew we had each other but, also more significantly, we knew we had an awesome God who was actively caring for us. That sense of care became even more apparent as we traveled through a couple of early spring snowstorms that made driving through an interior range of mountains treacherous at best. My job was to deliver Belle safely to the clinic and the doctors, whoever they were, would take care of the rest.

Along the way we stopped and visited three sets of friends; all with different perspectives on our situation. The first couple viewed it as a great misfortune that demanded their unconditional sympathy and prayers. The second couple took the time to catch up on our news while favoring us with their hospitality. The third couple gave us some helpful advice and promised to keep in touch with us during the treatment. All three responses were extremely encouraging, at the time, in reminding us that we were not alone in the healthcare system however complex and threatening the problem was. All three couples followed through in their promise to keep in touch.

Our first encounter with the cancer agency came when we booked in at its lodge after our long and tiring journey from the Interior. It was like moving into another world - an almost surreal one at that where life and death come face to face for control of the human body. It seemed that every patient was treated with the utmost of care and respect even to the point of shielding them from outside noise or visitors. We quickly learned that the regimen of imposed quietness and privacy only belied the true energy of the place. Many of the residents we met that night, and at later times, wanted to share their personal fight with cancer. It seemed that everyone wanted to be known by the kind of cancer they carried. We met people who traveled hundreds of miles, without family, to live in sequestered quarters in order to concentrate on getting better. Obviously, the rules and schedules of an institution such as this lodge were meant to remind the healthy ones, like me, that there were very special needs of the not so healthy to consider. There

were those who had the most grievous forms of cancer ravaging their bodies yet they all seemed, to a person, to be hopeful of making it and restarting their disrupted lives. A small group of 'terminals' could be found out on the front porch puffing away on their cigarettes because they knew full well that it was pointless to stop.

The next morning Belle and I had an appointment for a preliminary examination with a Dr. Penn. The night before, Belle had taken a quantity of barium in preparation for a CAT scan. This time she was going to have a thorough pelvic exam, extensive blood work, and chest x-ray as well as the CAT scan. This would take us to four floors and four different doctors, all specializing in some aspect of cancer. The routine was simple. The person accompanying the patient waited, read, looked around and, quite often, just stared off into space. Early into our visit as Dr. Penn was viewing the cervix through the speculum, one could see the concern grow on her face at the mess she saw. She told us that there was a large six to seven centimeter squamous carcinoma covering the cervical canal. It had literally doubled in size over the last three to four weeks which, according to some sources, is a normal rate of growth for invasive cervical cancer.

Before leaving the agency for lunch, she told us in a matter-of-fact way that she really needed more time to analyze the data before deciding on a course of action. It was plain to see that this was not going to be an easy call. Was she just being naturally cautious in her search for the right answers or was she trying to spare us the terrible truth that there was no hope for Belle?

Lunch that day at the lodge had to be the most uninspiring event of my life. It was like going through the motions without even noticing what one was eating. The moments of prolonged silence lengthened throughout the course of the afternoon. Gone was the sense of confidence we might have had when we first arrived. Those stories from the previous night offered no comfort whatsoever. Now it was crunch time! The oncologist that morning had appeared to be reserved about Belle's chances of making it and, by mid-afternoon, that began to really wrench at my heart. Had we gone through the frustrations of these last couple of weeks only to learn that the cancer had spread beyond the pelvic wall and, consequently, would not respond to radiation therapy?

I have to admit that my self-pity, at that moment, was probably at its peak, and my trust in God and the doctors at its lowest. The calm reassurance that I showed going into the agency that morning was gone. The wait that ensued seemed like waiting for a judge, in Dostoevskian style, to be imposed a death sentence. Utter helplessness and misery! I recall making a couple of telephone calls to old college friends to ask for their prayers, and this did bring some momentary relief. Meanwhile, Belle was taking some much-needed sleep on the adjoining bed in the room. Ten minutes to go before the fateful appointment with Dr. Penn on the second floor of the agency, and time seemed to drag on interminably.

It was time now to go and face reality. 'Be brave' my mother used to tell me before giving me that evil-tasting and vile medicine – cod liver oil. It was at that moment I resolved to take whatever bad news was coming and handle it with dignity and maturity. My self-pity was over, and I was ready to proceed to the next step in our relationship as husband and wife: loving her in sickness or in health. Believe it or not, those wedding vows many of us parrot on our wedding day have very little value unless tested under the most extreme circumstances.

The nurse directed us to one of the many little side rooms on the second floor where we were to wait for Dr. Penn. About five minutes later, the same diminutive Oriental oncologist, who had seen Belle for the all-important morning examination, walked in pulling a machine behind her that looked like an oversized respirator. Her facial expression did not wear that same grave look

from hours before when she frankly told us that it didn't look promising. Now she looked decidedly more composed.

She turned to me and said, "We're testing your wife's oxygen intake before treatment. We think she has a chance."

Suddenly, it dawned on me as I sat transfixed on that hospital seat - the cancer had not spread beyond the pelvic wall, and Belle was going to undergo treatment. That must mean she wasn't going to be assigned to palliative care and virtual termination.

I quickly turned to face Belle who was stretched out on the examining table and said what any typically relieved male would say under similar circumstances to the most cherished person in his life, "I love you, my darling," and planted the biggest kiss on her warm brow. A big smile broke over her face as the truth began to sink in.

"I hope those comments were intended for me and not the doctor," was her follow-up wisecrack. The tension and fear had gone, and hope had been restored to our fretful lives. There would be weeks of radiation, chemotherapy and surgery to deal with, but that prospect didn't steal the joy and thrill of the moment. As we were to learn later, Belle, with this welcome reprieve, was still not considered a good odds-on-favorite to make it over the long haul. From that point on, we learned the importance of living for the moment or the day.

That evening, Belle and I drove out to a local beach, cuddled up under a blanket on a park bench and watched the sun set over the ocean. What a truly delightful time in my life when God, in His sovereign will, decided to give Belle a fighting chance. The next twenty-four hours would be spent making some decisions as to how to organize our lives around daily visits to the agency for some simple but energy-sapping therapy. The actual treatment was around forty seconds with three to four minutes for preparation but the side effects lasted for many months.

As an outpatient, Belle had the much-appreciated luxury of being able to get around depending on her stamina. We reasoned that one main recreational activity a day would have a very therapeutic effect on Belle personally by improving her mental outlook. Reading in the park, visiting flower shows, attending concerts, walking and simply resting became part of a new extensive lifestyle that evolved for us throughout the first six-week cycle. There was also the challenge of finding an appropriate apartment that would grant us a more independent lifestyle than that offered by the lodge. We lucked out and found a nice little apartment in a moderately fashionable district about nine blocks away from the agency. It was comfortable enough to call a temporary home and allow us the freedom to come and go without disturbing anyone else's schedule.

As we were to learn very fast, much of our spare time was going to be taken up with helping other friends through a similar ordeal as well as researching the cause-and-effect of Belle's cancer. What limited knowledge we had on the potential of cervical cancer to kill only affirmed how blessed we were to have a modicum of freedom.

The regimen was for Belle to take a certain number of rads of radiation in the pelvic region five days a week so that, over a period of time, the main tumor would shrink and be destroyed. This would be supplemented each week with a five-hour session of chemotherapy. Belle would take cisplatin - the new wonder drug - to provide the double knockout punch for killing any cancerous colonies in the upper or lower pelvic regions and anything that might have escaped into the lymphatic system. In the days to come, there would be appointments with nutritionists, chemotherapists, gynecologists, cytologists and radiologists to get a handle on the true extent of the cervical cancer in Belle's body. It will always amaze me how many scientific assumptions

went into plotting a virtual external war on an internal and unseen enemy. The radiotechnicians, with the aid of a CAT scan and pelvic x-ray, formed a map of the malignant area. They then pinpointed the areas on Belle's skin within which the high beam radiation would be trained for a very short duration of twenty seconds. Belle's skin had several interesting tattoo marks that allowed the technicians to do their work without re-plotting the target each time. The whole process became so routine that after a number of visits it was a simple matter of Belle turning up, changing clothes, waiting to be called, being treated in the space of five minutes, getting the next appointment arranged, changing clothes again, and leaving.

The actual physical effects of burned skin, nausea and fatigue seemed to occupy most of Belle's attention after each treatment. Each of these small irritants challenged Belle to come up with coping strategies. Cornstarch was to be used in the place of talcum powder for the burned areas, anti-nausea medication for the queasiness and extra sleep to combat the tiredness. The only indication that there was any physiological progress made at all came from the good results of the weekly blood tests and checkups that showed tumor shrinkage. Hemoglobin and corpuscle tests were the main gauge by which the doctors could determine if Belle' s immune system was withstanding this awesome nuclear assault. It is expected that the healthier a person's constitution is, the better their chances are of surviving a major infection.

Doctors generally recommend an outpatient like Belle to adopt a successful daily routine as the best way to overcome loneliness, fear and boredom. Her constant need to have both flexibility and consistency built into her plan in order to get lots of rest and exercise remained one of her biggest challenges. This was made even harder by the fact that there were long stretches between her treatments that needed to be filled in so as to prevent her from being bored. For us, the plan consisted of spending designated times at the agency for both treatment and research, being outdoors exercising and recreating, socializing and fraternizing with old and new friends, taking care of domestic needs such as preparing meals, laundry and reading. In effect, we were learning to break from the old routines and vary our lives in ways the average person is never privileged to experience.

Chapter 3

A Time for Consideration

Belle's first cycle of treatment ended a month and a half later with little fanfare. She did have two tricky internal procedures to endure in the last two of the six-week cycle. These were done overnight, as an in-patient, and took approximately 16 hours each. The operating room and anesthesia were used in order to insert two metal rods into the vaginal canal. In the internal radiation room, microscopic radiation seeds traveled through these rods which were attached to a machine. This allowed treatment to engage the site of the tumor. As shown later in pathology reports, this operation reduced the carcinoma to almost nothing. Every time the technicians stopped the procedure in order to enter the room, the machine immediately sucked up all the seeds from inside the rods before the room door opened. This retrieval process was a precaution against any radiation leaks. The hospital officials even put a sign outside the door of the room forbidding any public access. The only brief visits with Belle throughout this complicated procedure came when the nurse stopped the machine to check that everything was going well with her patient. Otherwise, I had to be content with periodically looking at her through a small viewing window in the secured door.

It was the opinion of her oncologists and chemotherapists that, as she had responded very well to all the possible side effects of the drugs and radiation this first round, it was time for a break. She would be discharged to go home for six weeks or more to heal from the first round, before coming back for a radical hysterectomy in mid-July. This operation was to remove or exenterate the organs in the pelvic area thus preventing any possible recurrence of cancer.

While the weather was turning summery in the city, e-mails were coming from home, enticing us to go there as quickly as possible. However, the last two days before actual discharge proved to be most pivotal in determining what we would learn from this whole ordeal. Just around this time, two events happened that irrevocably changed our whole perspective on the power of cancer. These two situations would move us from the position of simply receiving treatment to the level of becoming more knowledgeable about Belle's particular circumstances. It would now become a matter of learning everything worth knowing about the disease and sharing our findings with others. It was at the end of Belle's last session of chemotherapy that the internist came up and congratulated her on successfully making it through the treatment. According to him, all vital signs looked good and that was the extent of his concern. As he pored over Belle's chart, we asked him if it were possible to take a quick peak ourselves. Imagine requesting permission to see one's own medical records! It showed how uninformed we were of our rights! He, with that never-to-be-forgotten, fuzzy-wuzzy perm that kind of reminded me of a former Canadian hero named Ken Taylor, gave us a disarming smile before turning over the bulky file as if it were no big deal. In all the years that Belle and I have been married, we had never seen each other's medical records. There is reason to believe that our naïveté was any different from countless other Canadians. I would guess this is the case with most Canadian couples simply because the need to know never occurs.

For the next half an hour, Belle and I scoured documents that described hospital visits, doctor checkups, blood work and Pap smear testing. At the time, we had no clue as to what we were

looking for, if anything, except that curiosity got the better of us. Then came a moment we will never forget. There, lying open before us, was her official Pap smear transcript: the written communiqué between the lab and our doctor concerning the quality of smears rendered through a very simple biannual test. It said, under the heading of May 15, l998 that the result was negative but with difficulty reading it because of exudate, no cells, and a recommendation to the doctor to investigate the abnormal bleeding. After studying the page carefully for a couple minutes, I turned to Dr. Sweet and asked if the local doctor was expected to follow up on that recommendation. Without any hesitation, he responded that, most certainly, excessive bleeding should be checked because of the possibilities of cervical cancer.

In the hospital literature that we had read over the previous two months, heavy and uninterrupted bleeding is usually a strong sign of the presence of either 'in situ' or invasive cancer. That much we knew, and now something seemed to punch us in the solar plexus. A lot of things were coming into focus. Belle's heavy bleeding, her doctor's possible cavalier and absurd treatment of the problem with iron tablets, and, now, this seemingly wanton disregard of instructions from the cancer agency added up to one suspicious case of incompetent health care. I remember revisiting Dr. Sweet a couple of times that day because I wanted to be sure I had the right interpretation of the transcript. Medical terminology such as exudate, endocervix, endometrium and countless abbreviations needed explaining. Over the ensuing months there was more to ponder as to how these terms would fit together to provide a complete picture of causes and effects.

Just before Belle was preparing to go in for her final internal beam treatment, we quickly drafted a letter to the College of Physicians and Surgeons expressing our concerns that certain doctors had not followed through on the Agency's recommendations for further investigation of the excessive bleeding. In our province, the college is a governing body that helps enforce medical and ethical standards by investigating patient complaints concerning many different levels of doctor care. Our main concern and conclusion at this time was that our local doctor had failed to take expedient action in checking out Belle's abnormal bleeding before it led to invasive cancer.

Our only focus was the Pap smear transcript, which told us what we thought amounted to flagrant disregard for a patient's welfare. After careful editing, and having it vetted a further time by a friend, we sent the letter to the college expecting a speedy response and prompt solution. A week after we returned home, we got the former in the form of a solicitous reply to the effect that the college was genuinely interested in investigating Belle's complaint but would require additional information and patience on our part because the investigation was generally a lengthy process. It was only an investigation and no discipline would result from its findings. So much for a speedy process! I wonder where we got that notion. It would take many months before we would learn the results that, in turn, would open another chapter or two in our evolving lives.

The second shock came on the last day of Belle's first cycle of treatment, and it involved our very good friend from our local church mentioned earlier. She was in getting extensive treatment for ovarian cancer. We had checked out around midday after saying our good-byes to Jane and her husband in her hospital room. This very brave woman had been admitted as an in-patient, in very dire straits, about the same time as Belle. Over the month and a half of our stay, a number of friends and visitors had witnessed her undergo a Herculean feat of making some progress on shrinking a massive Krukenberg tumor (fifteen to twenty pounds). This was her

second bout after an earlier stint of breast cancer two years before. When she was admitted to the cancer agency this time, she was in very rough shape due, in large part, to a fast growing cancer and a lot of dithering on the part of local doctors. Her restricted breathing and fluid build-up in the lungs were, in hindsight, overt signs of a death struggle about to begin. Her remarkable recovery from the previous breast cancer reinforced in her heart and mind that there was yet another miracle in store. In the closing weeks of our stay, she was probably receiving some of the heaviest chemotherapy available (if 'it doesn't kill you it'll cure you' kind), with having her lungs continually drained and all kinds of blood work done to monitor any improvements. Through all the pain, indignity, fatigue, frustration resulting from bedsores, collapsed veins and labored breathing, Jane always managed to give that big broad Texas grin of hers when anyone came into the room. In all our conversations with her, she constantly referred to God's all-sufficient grace to carry her through the hard times. As we said good-bye to her that sunny Friday morning at the hospital, Belle and I were fully convinced that she would, eventually, return home in complete health.

Little did we know what was about to happen! All through her involved chemotherapy protocol, doctors were playing a fine balancing act between thinning her blood to prevent an embolism or allowing it to thicken (which could cause one to form) to increase its cancer-fighting properties. It would be safe to say that she was on every clot-buster available and was being watched closely for any possible signs of trouble. That Friday night, after an active day of treatment and some light recreation, she suddenly collapsed and died as her husband lifted her into bed. The ever possible but hardly thinkable had happened. The enormous human effort, exhilarating at times, which had gone into keeping this very fine person alive, was gone in a moment. Nothing could be done to ultimately save her even with doctors and orderlies making all kinds of valiant and last-ditch efforts to revive her with CPR (Cardio-pulmonary Resuscitation).

In retrospect, both these incidents taught us a lot about getting past appearances and learning the real essence of a problem. For example, a superficial flip through Belle's medical chart would indicate that everything was in place in terms of a chain reaction. The general consideration is that she had a serious problem that needed handling right away, and the agency was prepared to do it without a moment's hesitation. The specific concern only came to light after the treatment began to take effect and was found in the question: why did Belle contract this disease when a regular Pap smear test is meant to detect it in its early stages? We wanted to learn who was responsible for not informing Belle of her choices for proper care so that other women could be made aware of how to avoid a similar situation.

In Jane's case, the issue of her survival was slightly more complex and puzzling than was Belle's. How could a person, who had such an ardent passion to live, and showing some improvements, suddenly die? The answer lies in how limited we really were in viewing Jane's case as opposed to Belle's. In the former, we saw the outward bravery and determination of a woman bent on overcoming yet another medical crisis in her life. Whatever medical insights we had about her diagnosis were filtered through Jane and her husband. Second-hand information, while eagerly sought after, should never be the main basis for expecting a person to get better. Where we quite often don't know what's happening, we pray and place our trust in God for her deliverance. Jane did that all the time, and God did eventually rescue her from a bed of pain and suffering by taking her home to be with Himself. We wrongly assumed that Jane would make it all the way back because of the enormous effort already expended to that end. Little did some of

us understand that her chances of recovery were severely impaired by a weakened immune system.

Questions still surface occasionally in my mind about Jane. Would she have had a better chance of survival if her team of doctors had agreed on a diagnosis earlier and then commenced treatment sooner? Would we, as her friends, have been any less effective in our support if we had known the true extent of her deteriorating health? All moot points now because she's not around.

In Belle's case, which was quite different from Jane's in the sense that chances of recovery were infinitely more favorable, we found a piece of the puzzle that assisted us in investigating a fresh batch of issues such as negligence and standard of care. We were now out of the critical treatment stage and into the recovery phase where the view of things suddenly became clearer. For a patient like Belle, there is nothing like having the freedom of being able to make informed decisions that will get a person closer to the truth. In Jane's case, right up to the end, she never really knew what exactly was wrong with her though she suspected it had to be very serious. There were as many opinions as there were doctors with respect to her problem, and chances of overcoming it diminished with each passing moment. Ovarian cancer was only reached as the final verdict after the autopsy following her death. There are a number of us who will forever ask the question: could her life have been saved if decisive action had come early in the game? For a woman with a previous history of cancer, perhaps, too much time had been squandered with considering useless and erroneous opinions instead of rendering effective care.

Chapter 4

A Time to Recover, Restart and Reconcile

Returning home after some time away is always pleasurable, under any circumstances, especially when it involves being reunited with children. A homecoming is an event that best signifies the completion of a chapter in our lives and a slight hiatus before the next one begins. For Jane, her return home was of a different sort in the sense that she went home to her Heavenly Father. For Belle, it was a case of returning to her community as a person who had beaten incredible odds and was prepared to start a 'normal' life again.

In our married life, we have become incredible creatures of habit and routine in our attempts to stay on top of things. What is often missing in our house during a lengthy absence is that intangible presence of upkeep. The moment we set foot inside our house on that rainy Saturday night, in late May, a number of jobs immediately presented themselves for completion. Granted, the place seemed to be reasonably well looked after but still lacked the good housekeeping touch that Belle brought to it. A quick check with our sons revealed that the tomatoes were effectively transplanted, the carpets had been vacuumed and the grass had been mowed. We were already informed, by e-mail, that our younger son was maintaining good grades at school, completing his work experience program and continuing to work part-time.

A brief chat with Peter, our older son, revealed a slightly revised update of his alleged achievements from what was previously reported. He was badly stuck on a very challenging advanced calculus correspondence course but still trying to create the impression that all was well. Having us home safe and sound probably was enough for him to come out and admit that things weren't going quite as well as he had reported. It suddenly occurred to me that, as his father, I was really the one at fault for having put all kinds of pressure and unrealistic expectations on the young man during this very trying time in his life. Here was a young man, trying to shield a hardheaded dad from learning, perhaps, for the first time, that his son might have failed to do well in his correspondence program. Rubbish! I was the real culprit in this piece for pushing our son to hide his frustrations. From that point on, I resolved never to try and run Peter's life again like some petty dictator, setting artificially high standards of achievement under the most impossible of conditions.

After a big hug - something we had not always found easy to do - I told him how proud we were, as parents, to see him take the big step and enroll in a university accounting program. Sure, we would be there to advise but never to rule. Those days were gone. Maybe that realization would never have come but for the fact that we had to leave to take care of Belle's cancer. The learning curve comes in all shapes and sizes for those who are willing to be taught anew the significance of relationships. My problem, as Peter's dad, was that I had incorrectly assumed that I was in control of the situation. Ironically, this was a predicament I had created, in the first place, because of my unreasonable expectations and my own latent fear of insecurity.

The welcome that Sunday morning in church from all and sundry was equally touching. Each of the ladies gave Belle a carnation as a token of their love and care for her. I remember telling the congregation that morning how good it was to be back with our friends and how appreciative we were for extensive prayers offered on our behalf. Jane's husband had returned home the

night before and was sitting in the pew in front of us with his three daughters. In a short conversation at the close of the service he told me, composed but with a tearful look, that the autopsy had revealed the presence of a clot blocking one of the main arteries of her heart. Ours was an easy row to hoe in comparison to what this man was going through. The last two and a half years for him had been more bane than blessing because of the never-ending concerns about Jane's health. What we admired in her husband in the form of stoic determination and a brave front also worried us. The loss was great and the grief deep but emotions seemed to be too well kept in check. For Belle and myself, healing would come in the positive and noble qualities filling our lives again. For Jane's husband, it was simply exercising faith, returning to work and allowing the flow of time to, eventually, erase the pain of a great loss.

The return to work was as if I had never missed a beat. My classes had been well taken care off in my absence. Most of my students had kept up with the work without my coaxing and coaching. This led me to see myself as somebody a lot less important than a greatly-to-be-feared ordained teacher of much worldly wisdom. While I was very delighted that the transition back into the classroom was a smooth one, there was the realization that I needed to turn up the heat to get my weaker students through the course and ready for final exams.

One of my colleagues summarized the school as being an uncharacteristically dull place during my absence with the exception of a colleague's firing. Here was a teacher who had lost his way in the job and was quite unprepared to find himself. His argument over the years was that no teacher had been fired for incompetence for as long as he could remember and, besides, all the administrators were incompetent anyway, so why worry. What a surprise he got in the end! It was just a question of when the educational system would finally 'call his bluff'.

Our return also signaled the requirement for some critical changes in our lives. In the first week, we agreed on the need to change doctors. Belle made some initial inquiries as to whether doctors were taking any new patients and came up empty-handed. It would appear that each time she mentioned who was calling, she would get a polite but firm reply that the doctor was not taking on new clients at this time. I had that uncanny premonition that very few doctors were willing to deal with a controversial situation such as Belle's. While the agency down south had told us that we were now dealing directly with them, there was still the need to take care of basic concerns that might signal a bigger problem down the road. I decided to do some phoning myself and contacted one of the doctors who had kindly refused us earlier and pled our case. I mentioned the 'C' word and told them the predicament we were in. To my surprise, they seemed to be quite aware of Belle's case and were in the process of reconsidering their previous decision. As it turned out from that point on, Belle received valid, as opposed to bogus, help from this husband and wife team who seemed to be clued in on employing modern rather primitive medicine.

The other timely decision made during this time was to go looking for a lawyer to review our case. Our search for a legal opinion took us to a so-called legal eagle in the field of malpractice litigation. Shelley was very up front with me in saying that if it wasn't a million-dollar action it wasn't worth fighting. One would have more success filing a complaint with the provincial governing body with the objective of getting the Doctor disciplined, and possibly barred, than going through the courts. To test out the evidence in our case, she would require $1000 to hire an independent adjudicator to assess the facts. She would only proceed with the case if she felt that there were provable damages. She did concede, however, that the grievous nature of Belle's sickness might merit claiming for loss of future income. Since this was only an exploratory stab,

and we didn't have our complete 'kit' together, nothing more came of this inquiry. Something told me that there were other leads more promising and to keep looking!

School ended on a very quiet note. Both our sons were continuing with their summer work and the weather was warming up a tad. The fruit was appearing on the vine, and we made plans for a trip to the prairies with my parents. Belle's operation was scheduled for the middle of July so a little holiday into the great outdoors might be a welcome tonic. My stepfather had always wanted to show us his old stomping grounds where he grew up as a boy. My mother also wanted to go back to where we had first lived fifty-four years ago in coming to Canada. After tying up business in Edmonton over the Canada Day weekend, we all drove northeast into the mixed farming belt of Alberta. Lots of rolling hills, grassy plains and groves of poplar trees to meet the eye along the way. This was a peaceful, prairie landscape with lots of reminders of a pioneer-settler mentality from years ago: eastern church cupolas and spires, deserted hay barns, rather weather-worn looking, ramshackle, square-timbered style houses forlornly but bravely standing out in the middle of the open prairie.

On our travels, we took a trip out to my stepdad's old farm - or what was left of it - where he grew up as a boy. This included a visit to see one of his old school chums who still lived on a corner of the old farm. This was followed by a side trip out to Frog Lake to see a little bit of Canadian history being showcased at the scene of a massacre that triggered the North West Rebellion of l885. Since this memorial to the death of eleven white settlers was right in the middle of the Frog Lake Native Reserve, the local band council had intentionally played down its presence as a very blatant reminder of old grievances. One could drive right past it and not know that it was there because the sign was away at the back in the bush, and all that could be seen was an unassuming cairn. Meanwhile, two miles down the road, towards the lake, stood an easy-to-see marker to the memory of Louis Riel. The somewhat futile search for the ever-elusive memorial cairn commemorating the site of the tragedy gave us lots to think about when we finally pulled out to go to Lloydminster for the last leg of our journey down memory lane.

Our arrival in Lloydminster, later that afternoon, brought us almost full-circle to the first place my parents had settled down in after coming out from Ireland in l954. Of course, there were the old landmarks to be seen such as the high school where my dad had taught, the hospital where my mother had nursed, the house along the highway where we lived and the elementary school my older brother attended. After asking around, we managed to locate the schools because they were still standing. However, the hospital was now a senior citizens' complex, and the lot where our white and yellow siding house once stood was now occupied by a 7-Eleven convenience store. I had no trouble reflecting on the immense and complex changes that had occurred in our lives since that day in early July, l955, when we pulled out of Lloydminster in an old l949 Pontiac Monarch, with a homemade utility trailer behind us, heading for the West Coast. To say the least, there were enough of the old markers and monuments left at the original site to give us an idea of where this so-called trek began. Every story, like Belle's encounter with cancer, has to have a beginning. It is good sometimes to return to that starting point so as to grasp the extent of our travels and personal maturation. But like our stopover in dusty, dirty and windblown Lloydminster, it is also advisable not to dwell too long on the past.

A week later, Belle entered her second cycle of treatment involving a radical hysterectomy. This procedure was to be done by the skillful hands of one of Canada's leading gynecological surgeons. The hospital had one of the best records for successful hysterectomies because of the low incidence of having to do them. In Belle's case, it was both necessary and expedient to wait

for her to recover from the previous cycle of treatment before doing the operation. It entailed the removal of the ovaries, fallopian tubes, uterus, and cervix so as to eradicate any remaining traces of the malignancy. As pathologies were to show later, there were still traces of a tumor on her left ovary. This stint in the big city became the time when we asked people in the know some very hard questions as to the quality of care that Belle ought to have received. Since we were still trying to make sense of the terminology and jargon used in many of Belle's charts, those early questions quite often missed the mark. Gradually, as a surgeon, an oncologist and a researcher would patiently explain the process of cervical cancer, we began to understand. They told us the conditions through which it developed into an 'in situ' lesion to eventually become a tumor that grows into the tissue before metastasizing via the lymphatic system to other organs of the body. In the week that Belle was recuperating from her surgery, we began to see that it wasn't going to be easy to pin someone down on what should or could have been done to prevent the cancer from progressing to the point that it did.

After a brief holiday with my parents, we decided to head back home to get ready for our real summer vacation in Oregon with our sons in late August. We also needed to relieve Norm and Dee who had taken on the responsibility of looking after our business in our absence.

In the past year, we had joined with this very fine couple in a business venture involving the wholesaling of a wide range of home products. Belle and I really admired the help and encouragement Norm and Dee had given to us as we took on the 'Canadian Dream' of running our own business. We will always appreciate them for selflessly standing in for us by dealing with new clients while our attention was elsewhere. Keep in mind that they were two old-age pensioners – he a former lawyer, she a housewife – who still worked doing odd jobs to pay the bills. We never really knew how much of a struggle it was for them to keep working under these trying circumstances because we never saw or heard them complain once. If things had gone right for them from the beginning, they would never have been scrambling to make ends meet later; such is the lot of humankind. All told, Norm and Dee were still the people, along with our immediate family and many others in the community, who were quietly helping behind the scenes to get our lives back on track.

Chapter 5

A Time of Both Sorrow and Joy

August to September, 1999

Upon our return home for the fifth time this year, there was that latent, optimistic sense that, maybe, this August would be the time for finally getting our lives back to a semblance of normal. It would be a time to enjoy what was left of our holidays in the sanctity of our own home. But, alas, everything from simply balancing a check book, to writing letters, to visiting with business clients, to consulting with doctors, to preparing for a family vacation in Oregon needed to be done in a hurry. So much for taking it easy! Additionally, on our way home, we had stopped off to visit with an old lawyer friend to discuss the merits of Belle's case. While he was eager to help, he did point out some potential pitfalls. He left us with the thought that friends do not always make the best lawyers. A week later, he sent us an e-mail suggesting the name of a lawyer whom he had shared a case with in earlier times. This lawyer worked in a big city firm specializing in malpractice and bodily injuries. We knew we might be on to something very special when a lawyer recommended another lawyer and, in the same breath, called him a very honorable man! If the stereotype of lawyers being 'sharks in the big pool of life' was remotely true, this approbation might also serve to remind us that there is truly honor among 'thieves'. For the time being, that information remained in an inactive file because of the whirl of things going on in our collective lives at this time.

During the first couple of weeks home, we waited anxiously by the phone for pathology reports that would show how the first round of treatment had gone. Keep in mind, radiation and chemotherapy are treatments that initially show very limited evidence of success. The patient is mainly kept in the dark as to a successful prognosis until it can be conclusively shown that the tumor in question has shrunk or disappeared and that there are no further adverse reactions. For uterine and cervical cancer, removing the formerly infected area and subjecting it to microscopic review is the only means of determining if the therapy has worked.

When the news finally came through, it was one of those ambiguously good and bad situations. The entire tumor, as the primary source, had disappeared but a small trace of it remained in one of the ovaries. Because Belle had made such tremendous progress, it was felt that another round of prophylactic treatment of the para-aortic lymph nodes would succeed in preventing any cancer from breaking out further. This meant another two months for Belle to receive radiation at the agency. Our hearts were beginning to rebel at the thought of more treatment; our minds, on the other hand, wanted to accept the rationale for having one more cycle of treatments as a precaution against a possible relapse. This procedure was finally set for late September with no great urgency attached to it.

Mid-August, near to our departure time for Oregon, Dee, our friend, suddenly became seriously ill. There were dizzy spells, loss of appetite, fatigue and lots of diarrhea. Dee was in her mid-seventies and was emphysemic, resulting from a long history of smoking, though she had successfully stopped fifteen years previously. A week of having her languish around the house in a sickly state finally motivated Norm to get her admitted to the local hospital for a

checkup. It was there that the doctors, through a series of chest x-rays, detected a relatively large mass on her right lung of the slow-growth variety.

The dizzy spells were more than likely due to an inner ear infection that caused imbalance and poor motor functions. Like Belle's pelvic lymph node that became infected, the dizziness was an early warning sign that alerted her doctor to a much larger problem. There was Norm trying to keep his bookkeeping and wholesale businesses together and, at the same time, tending to his sick wife. What tenderness and devotion he often showed her under the most trying of circumstances!

Dee was airlifted out one Saturday afternoon, without Norm, to the big city for more tests and possible surgery. We had spent part of that day with her in her room waiting for the news that an air ambulance was ready to ferry her down. Those moments of holding her hand and reassuring her that all was going to be well were very precious in affirming our friendship. It was almost as if planned. We stepped out for a just a few minutes, or so it seemed, to take care of some business, and the room was empty when we returned. Even Norm didn't get a chance to see her off on the final big journey of her life, though he traveled down to Vancouver a couple of days later to be by her side.

Belle and I were blessed to catch up with them at the hospital a week later just before the crucial surgery to remove a major section of Dee's lung. She and her husband had made an informed decision to go ahead with the operation, even though it came with a one-percent chance of failure because of clotting. The other option was to do nothing but languish in pain and suffering for another year before succumbing to the horrors of lung cancer.

What had always impressed us most about this dear soul was her genuine and warm sense of humor in the blackest of moments. The broad and confident grin and the little chuckle were simple reminders that this woman had learned, in her lifetime, the virtue of being happy despite being beset by menacing circumstances. Her last number of years had been plagued with poor health such as a chronic shortness of breath and high blood pressure. Even trying to find her room in that great labyrinth of St. Paul's Hospital had a humorous side to it. We took the wrong elevator and found ourselves down in the basement next to the morgue. With all those oblong caskets stacked in a corner, the air somewhat cool, the lights dim and a hard-to-read sign saying in macabre fashion, 'This Way to the Morgue', it certainly didn't appear that Dee was holed up here. After visiting her for a while, we said our good-byes and left for Oregon. Four days later, Norm phoned us from Canada to tell us that Dee had passed away from complications resulting from a blood clot in her remaining lung. What was truly amazing about Dee was that she opted for the most perilous treatment that offered a one percent chance of blood-clotting, rather than keep the status-quo and be guaranteed of only a very reduced lifestyle for the remaining months of her life.

Belle and I are convinced that Dee showed us the strongest of characters under the toughest of conditions. Like Jane of only a couple of months earlier, her faith in God never failed in her hour of need. We had lost a very special friend, but it was not like we were ready to go into deep mourning over this one. The beautiful, sunny weather dominating the Oregon Coast that week was yet another perfect reminder of God's wonderful creation. Ideally, it was yet another case of 'God, Our Father, is in Heaven and all is well with the world'.

This was a time that our immediate family needed to be together before Peter went off to college. Out of these frustrating and sad times in our lives came the joy of being together in a natural setting that encouraged both rest and activity but no onerous work. For me, a simple

activity like flying a kite has always represented the sport that best combines both a sense of action and a position of rest in a natural setting such as the beaches of Oregon. Over these past couple of months, we had lost two very close friends, and Belle's recovery wasn't finished yet, but God had chosen to bless us with His strength in the form of our immediate and extended families.

Good news came from overseas when Belle's sister and brother-in-law from Ireland announced their plans to finally come over and see us in September 1999. This would be their first visit ever to Canada so you can well imagine the excitement we had in preparing for their arrival. We figured that it was probably Belle's illness that prompted the decision. The Irish, as a race, may be famous for wandering the face of the earth in search of new livelihoods but Irish farmers, who have some land to take care of, generally stay at home. This particular couple was no exception to the rule. Their coming at harvest time required other members of their family in Ireland to step in and fill the void.

The time of their arrival and departure was perfect to the day. There was that fifteen-day period, from the time we came back from Oregon to when we left for the third cycle of treatment that represented the window of opportunity for a visit from our relatives. Belle and I have always been people who enjoy showing other people, especially family, an organized and action-packed time. The way it worked out, none of the many activities we did or places we traveled to seemed to tire Belle out. This was a special occasion that she wasn't going to miss for anything. The lingering effects of fatigue and nausea from earlier treatments were not as frequent. The sleep she was getting, the positive attitude she was showing, the improvements in her health, and the prospect of having members of her family over for a visit were enough to give her a newfound zest. Added to which, the wonderful warm weather of an Indian summer seemed to give that special touch of a good time.

This seems to be the year that just when we feel we have momentum and that things are beginning to work out, we are ambushed by the unforeseen. Our friend, Norm, just turned widower, came over for supper and a chance to meet the Irish relatives. It was obvious that Norm truly felt the loss of Dee, his wife of some forty-five years. We could see that 'old' Norm - full of drive and talk - was not there. Instead, he was a listless and dispirited man who was anything but his normal self. He mentioned, during the course of the evening, that he had some real concerns about pains in his chest, and the lagging and tired feeling he was experiencing more and more. He was thinking of going south to have this checked out.

Three days later, we left for the coast after seeing our guests off at the airport. Our younger son, Eliot, stayed at home to keep house and continue his Grade 12. His plans were to graduate and train to be a computer animator. The day we left will be another unforgettable litany of misadventures and close calls. As we traveled along the highway, twenty minutes out of town, we hit a dog. As we passed through a town later in the morning, we almost knocked down an elderly native fellow who was crossing the street. The day culminated in another near scrape with some moose standing by the main road of another interior town that we passed through. Unbeknownst to us, Norm, around six o'clock that evening, had gone out to split some wood and had collapsed and died from a massive heart attack before help could arrive. We heard the bad news the next day when we visited our older son at college. He had just received an e-mail to that effect.

The very real temptation is to say that Norm died from a broken heart (whatever that really means) and leave it at that. Belle and I, in our loss of yet another important friend, rationalized

Norm's death this way. He had worked hard and long as a lawyer for most of his adult life. A couple of bad investments during his middle years had forced him and Dee to keep working well beyond retirement. They had moved up north to help a couple of their children get their lives back together and that was when we first met them. Time had caught up with Norm, and he was about to be squeezed out of a major consulting contract with a couple of local business ventures.

The stress and shock of losing Dee was the triggering event that lowered his immunity and caused an already overtaxed heart to fail with what had previously been normal healthy exertion. From both a sentimental and spiritual point of view, it was clear that dear Norm was lost in the world without his beloved and faithful wife, so God, in his infinite mercy, decided to take him home be with Himself (and Dee). Ever since Dee's illness, our mutual business dealings had dissolved, and yet we had some lasting benefits that went well beyond working with Norm and Dee as partners. They were people of integrity who did things on the basis of a principle and not a whim of fancy. On a number of occasions, we saw them absorb a loss rather than pass it on to a customer less able to handle it. Their home was virtually open to friend and stranger alike when it came to acts of charity. Doing the right thing was, for this couple, a matter of making the biggest positive impact on as many people's lives as possible in the shortest period of time.

It just so happened that their health broke down before they had completed their goal of being financially independent. In God's heavenly economy, the true intentions of the heart are judged as more important than the realization of some noble purpose. Sorrow at the loss of this fine couple is more than offset by the fact that they have passed on to us a very rich legacy of human goodness. We didn't get as far with them in business as we wanted to and that, in itself, was reason for disappointment. We did, however, see in them the importance of learning to put others first in everything we do, including business. They have to be the most conscientious couple we have ever met.

Chapter 6

A Time to Know and Act

September to November l999

The next number of months at the Cancer Agency were going to show us some very fascinating things about cervical cancer which, up to then, had for us been simply a killer disease. We had little inclination to probe its mysteries because we had been focussing mainly on recovery for Belle. Before we left home, we wrote a brief letter to the city law firm that our local lawyer friend had recommended weeks before. The response we received was very positive, and they wanted to meet with us at the earliest convenient date.

For the second time in the last couple of months, Belle and I carefully compiled another digest of all the events that had transpired in the last two years that even remotely concerned her health. All the information pointed to the May 15, 1998, Pap smear that was, in retrospect, severely botched. What we were confident of at the time - and still are - is that a certain doctor or doctors had a duty of care to act in a responsible manner in dealing with suspicious symptoms and didn't.

We recall quite vividly the experience of sitting in a very posh law firm's outer office, on the 40th floor of a skyscraper, in the middle of the big city, waiting for our interview with a lawyer and wondering what possessed us to take this step. I had often told my students in high school law to avoid, if possible, falling into the clutches of a lawyer. I might have even made a veiled reference to predatorial instincts and unscrupulous conduct in the same breath. As a profession, lawyers, in my judgment, represented a necessary evil that was less necessary than evil.

However, upon reflection, we could see that we had a serious need to get a legal opinion that either supported or refuted our claim of malpractice. Let's face it, only an experienced and competent lawyer - not a paralegal - was going to take our case on a fee contingency basis. What we didn't bargain for was a lawyer who was personally interested in gathering evidence to determine if we had the basis for a case in the first place. He made no firm promises but left us with the clear impression that he would turn over as many stones as possible to get at the truth. Thinking about that now, I have to conclude that lawyers are probably practiced at initially winning their clients'confidence. He did suggest, during our first meeting, that the process might take much longer than initially anticipated and involve more parties than originally suspected. Patience and persistence would be two major virtues that could invariably bring success. We also left that day, in late September, with the clear signal that we could become indirectly involved in investigating the circumstances of Belle's case. To keep busy during the next couple of months, Belle and I decided to research cervical cancer from all conceivable angles like symptoms, staging, diagnosis, cause, treatment, and prognosis.

To accomplish this ambitious goal would involve a complex strategy. First, we had to learn what was available for us at the cancer research library. Then we had to form a set of questions that were relevant to Belle's particular case. Then came the hard part with reading and comprehending dozens of articles and books on the subject (some of which will be covered in a later chapter - the periodicals on oncology and cytology were easier to read than the ones on

chemotherapy). After that, we then approached some specialist or authority who would confirm or reject our findings.

Some personnel at the agency and the research center got to know us because of the hard and, sometimes, awkward questions we would pose. We were always treated with respect and handled intelligently when it came to giving us forthright answers. We found that people were more willing to talk about a concern if we didn't come on like gangbusters or conceited know-it-alls.

By the middle of October, when the fall colors are usually in their prime, Belle and I were becoming quite conversant in the rubric of gynecological cancers and their various associated treatments. While oncology - the study of tumors - is hardly an exact science in the sense that it cannot accurately predict beforehand how the patient will respond to therapy, it does have lots to commend it in terms of empirical data. Tumor size, type of tumor, staging, a person's age, health and weight are all factors that have been extensively tested in co-variated studies as to their influence on effective recoveries.

Each day, right after radiation, Belle and I would slip up to the library on the fourth floor and scour the stacks and racks for the latest tidbit or gleaning on what was new in the field of oncology. The librarian and his staff helped us chase down leads on alternative treatments, the advent of cisplatin, the technology involved in the photon beam selectron, chemotherapeutic agents, gene therapy, Pap smear screening techniques and investigative procedures such as the colposcopy.

Here I was, away from my job for a couple of months, acting out the role of a student taking a crash course in human physiology, in order to find out what had caused Belle to almost succumb to a very preventable disease. The Internet, in respect of the countless number of open web sites on cancer detection, prevention and treatment, was also a valuable tool for establishing the all-important general standards involved in Pap smear testing. These sites included information on how the disease evolves over a long period of time. Most of the web sites had an e-mail address which allowed us to relay questions to these organizations as to what was the generally accepted practice or procedure. Our extensive findings will be discussed in a later part of this book dealing with the many medical and social issues related to Belle's case. For the time being, they amounted to trusting the efficacy of the Pap smear and heeding any one of a scattering of early warning signs such as abnormal uterine bleeding.

Belle and I have had some respect for the concept of cervical screening right from the start. It has its obvious limitations in the sense that it is really only an early warning device to prompt subsequent testing. Its apparent success rate, among many diagnostic ones, is very enviable. It comes with the proviso and corollary that, while it works for most women, it doesn't work for all. In research that we will share later on, we are convinced that the Pap smear's much ballyhooed success rate has many holes punched in it already in terms of its reliability.

It is not foolproof in being able to render reliable interpretations of samples that are in the in-between zone of being suspicious and somewhat difficult to read. This is because (a) the evaluation of the sample field is restricted to only a small segment of the slide and (b) any number of uncontrollable factors such as exudate (pus) and excessive bleeding could produce a poor-quality sample. Our cancer agency is now saying that cervical cancer is reappearing in the 21st century as a major concern because many minority sectors of the population are not participating in the Pap smear program. Like all statistics kept on early detection programs, much is made of the reduction in numbers of actual cases when more attention should be paid to

those who are the victims of bad screening (10% to 30%) and those who are neglecting to have the test in the first place.

True to his word, our lawyer sent us transcripts and updates of Belle's medical records over the last six years and court cases involving similar situations. Meanwhile, Belle and I continued to read a number of key articles that emphasized the need for the doctor to check out excessive bleeding especially in a woman beginning menopause. In conversations we had with administrative and medical personnel at the agency, they took the position that it was the responsibility of the local doctor to check out a suspicious symptom because it might very well mean the beginning of invasive cancer. A friend at the research center was good at encouraging us in our search for answers. He left us with the impression that a lot of cancer research is devoted to improving the treatment end of things while early detection still rests on the laurels of a fifty-year-old test. He admitted that while the agency might do a more-than-adequate job in saving lives, it wasn't any more adept than the local general practitioner in spotting the early warning signs.

To prove that life in the big city was not all drudgery and tedium of research and treatment, Belle and I took our bikes along this time for some recreation. This city, like other Canadian metropolises, allows for bike traffic by marking off special bike lanes on most of its busy thoroughfares. Like the Indian summer we left behind at home in early September, the good weather continued here. With the important exception of being separated from our children, we got the chance to do many of the same things we would at home with the luxury of being on a paid holiday of sorts. In reality, I would take the good health and demands of the job any day but, while that could not be guaranteed, extended leave under less favorable circumstances is the next best thing.

Once again, we planned our day to be really distinct from anything that went on in the clinic. Cycling took us down to the clinic for Belle's daily dose of radiation but it also took us in many other different directions within the confines of the city. While the skyline of the city and the mountains as a backdrop might be impressive from the sixth floor of the agency, they always had a way of beckoning us to come closer and investigate for ourselves.

There was the public library with its neo-classical, colossi look to wile away the hours reading in ultimate comfort. The numerous second-hand bookshops within a few city blocks of our apartment allowed us to browse and perhaps pick up an Iris Murdoch novel or a Bagley murder mystery. Then there was our favorite eatery with fresh fish and chowder on the menu each day. To get a better grasp of life on Skid Row, we would periodically step inside the Gospel Mission to have coffee with friends. There we could hear a colorful array of tales about life on the wrong side of the tracks. Then, if it were peace and harmony with nature and the outdoors that one was looking for, to ride, to walk around, or just to sit out in the park would fill the bill. If understanding history was your thing, a trip to the Holocaust Center and its many exhibits was the answer. Afternoon coffee could be had in many of the quaint and personable cafes along one of the many nearby streets. Admiring beautiful floral displays was as easy as attending the local botanical gardens just up the street. A good time of fellowship and spiritual renewal awaited us at First Baptist in the heart of the city.

Large parks and countless other little community parks were available as hideouts from surrounding noises for napping, sunning or reading. If we wanted to see the splendors of an annual apple festival in the midst of the changing colors of autumn, a trip out to a college campus was in order. If basketball was the game, the Grizzlies were often in town, with cheap

seats in the upper decks offering a reasonable view of the action. If seeing a dear shut-in friend who was rehabilitating from a bone-marrow transplant was called for, a visit to the fifth floor of the agency was as easy as a thirty-second elevator ride. If dropping in on our oldest son in college on a weekly basis took our fancy, which could be easily done by jumping into the car and driving across town. There seemed to be no end of activities to get involved in as long as we kept looking. A wide range of free and funky tabloids informed us about major happenings around the town up to a week in advance.

Once again, a certain amount of time in a typical day was given over to treatment, getting plenty of rest, taking care of domestic chores, reading, visiting, studying, sight-seeing and exercising. We reasoned that too much free or idle time would work against Belle's ultimate goal of recovery by giving us time to worry about the unknown. A carefully planned routine, with some flexibility, would eliminate that sense of being too prescriptive. What was very helpful for us was that Belle's treatment protocol was known a week in advance and could be dovetailed to accommodate certain special plans. The day we spent biking around a local Gulf Island is a case in point. We were able to build a whole day's outing around an early appointment. As we left the agency to catch the ferry, it was pouring heavily with rain and continued to do so until we stepped off the launch at the harbor. For the next four hours we enjoyed the sun that shone between the storms, so to speak.

Our determination to follow the routine to the letter was based on an earlier CBC weather report that forecasted a short clearing spell in the afternoon between incoming Pacific storms. Knowing the proper information allows one to act effectively in planning ahead. Belle's illness and all her treatments and appointments had caused us to tighten up on our time management without getting too obsessed with every last detail. We were finding that there could be room for some spontaneity within a well-organized day. However, without a sense of order, we hate to think what the experiences and events of the past few months would have amounted to. Timing is everything when your life is hanging in the balance.

In those last weeks of the third cycle - in late October - new developments were popping up all over the place. Our friend was being discharged from the cancer clinic's ICU because another patient needed the bed. She was recovering from a bone-marrow transplant and was making some progress in her blood count. She had been in and out of the hospital and clinic for the past eight months and was longing to get home to be with her family even under the most stringent of conditions. We recall clearly the day she took her first steps outdoors after the transplant. It was truly heart-warming to see this person making a tentative effort to get re-established as she walked over to the counter at the pharmacist to order a supply of life-supporting drugs. Standing next to her made us realize afresh how truly blessed Belle was in not having nearly the same symptoms and side effects that she was suffering. She was returning home to deal with a recovery period of at least a year and an uncertain prognosis. Belle, instead, was going home to enjoy another short stint of recuperation before returning to work with recovery not so clouded with the unpredictable.

The second surprise came in the form of a letter from our lawyers stating that they had uncovered yet another set of Pap smear tests that seemed to appear from nowhere. From our reckoning, we now had three different results that dealt with the same original test. There were also second differing records concerning two tests before the one of May 15, 1998. If a medical institution's job is to supply the patient with readily understandable data by which to make informed choices, these varying and conflicting results were only confusing us more. It was at

this juncture that Belle and I started to conclude that the quality of the Pap smear and its reading - not the Pap smear itself - were as much the culprits as anything in this whole affair.

Discharge or D-Day occurred on a Friday morning in early November. There was a real sense of urgency to get home because the weather was cooling significantly and our valley back home had experienced its first snowfall. We took with us not only the pleasant memories of being with friends but also a sense of a mission accomplished in regards to determining the cause and cure of Belle's illness. There were piles of records, documents, articles, and books to pack away in boxes for the long journey home. Dr. Penn gave Belle the final stamp of approval with a big hug and told us that while the third cycle had always been optional, it was the best strategy at the time given the potential for recurrence. We had learned the hard way that uncertain knowledge, when not acted on, can lead to possible tragedy.

Chapter 7

A Time to Make Sense

November l999 to June 2000

All the information on cervical cancer that we compiled over those last two months of treatment began to take shape in the form of a book soon after we got back home. We felt led to recount a story that might offer some helpful insights into the areas of patient care and rights. In order to bring this about, we had to be sure that the story would be both informative and useful to any persons choosing to read it. Nothing too technical so as to confuse the reader, but also nothing so simple as to gloss over the severity of Belle's case and others like it. Our main target group was obviously women but that could easily be expanded to include husbands, children, relatives and friends. We were also aware of the fact that this book would be written while we attempted to tie up a lot of loose ends in our lives. It was also necessary to act quickly on this project while the information was still fresh in our minds.

We would proceed from an outline that would basically follow the events covered in our diaries over a two-year period. Each chapter deals with a specific time in our lives when we encountered a new aspect of Belle's cancer. For instance, one of the underlying themes in the book relates to what happens when the patient is not properly informed of what's wrong with her. The theme here simply is 'to be forewarned is to be forearmed'.

Going into Christmas l999, and then into 2000, with all its millennial hype and pessimism, we had a growing sense of a brighter future. God had preserved us through a very tumultuous year with very little emotional scarring to show for it. The unfocused anger we once had, when we learned how sick Belle really had been, was now being channeled in more constructive ways. We knew what had gone wrong, and the time had come to get some answers.

One night, while I was clearing up some business, I happened to pick up the transcript of Belle's Pap smears to look at it again. My attention was caught by the May 15, l998, Pap smear that had been reread on July 15, l999, by the same agency. What caught my attention was that this was highly unusual. Here was a very public agency rereading something that, by definition of their protocol, was unreadable in the first place. A Pap smear, obscured by blood and exudate, should never have been allowed to be part of the record but discarded as a dud and a new sample requested. Rereading a bad sample in order to get a better result is like desperately trying to identify something that doesn't look any clearer the second time around but reporting it, nevertheless, as satisfactory. Think of the problems the agency might have if it were to admit that the smear dated May 15, l998, should never have been called negative when it was likely positive all along. Added to which, it appeared that the lab technicians never applied a double-blind test protocol for rechecking previous Pap smears for potential misreads. Every effort was made to square the results so that the Agency appeared to be consistently on track. The absence of suspicious cells meant a strictly negative outcome.

In this second reading, the technician had chosen another part of the slide to see what looked like a few suspicious cells embedded in an acute inflammatory background. Belle and I, once we

agreed that the May 15, 1998, Pap smear result was bogus and, perhaps, even a false-negative for other reasons such as lack of endocervical cells, decided to approach the Agency for some answers. What we got was an interesting combination of surprise, hurt, confusion, obfuscation and, finally, an admission that reading Pap smears was not a perfect science. There was that feeling that we had no right to challenge the work of an eminent cytopathologist and her team of associates.

Complicating this whole scenario further was the revelation that yet another surprise transcript of Pap smear results surfaced indicating that the re-readings of the June 1999 sample had been removed or sanitized so as to look like everyone in the organization was singing from the same song sheet. Our only conclusion was that two different parties were at work on Belle's Pap smears, and every effort was being made to iron out the inconsistencies in reporting by some mysterious in-house quality rechecking. There was no independent body overseeing the re-evaluating of the questionable Pap smears of 1994, 1996, and 1998 and, as earlier mentioned, no double blind test to protect the anonymity of the patient from the tester. If this procedure had been in place, the screening lab would not have known what it was being asked to review and, so, would not have been tempted to look for what they knew already existed.

We might think that we're dealing with a low-grade science where the technician and the cytopathologist make random calls on what they think are highly irregular cell growths as opposed to normal cell growths. Of course, there is supposed to be double-checking on every sample that looks questionable, but what about the ones that are mistaken for being normal because of some oversights in diagnosis?

Until this year, we both had no reason to question the integrity of the Pap smear or, for that matter, a prostate test. Now we're hearing some doctors expressing reservations about the reliability of both these tests. For example, the prostate test is limited to only an area count (i.e. the PSA - Prostate Specific Antigen) which is something that rises and falls quite regularly so should not be counted on as being very dependable. In the case of keeping tabs on a woman's Pap smear, some respected authorities suggest that it may be even all right for a screening agency to miss detecting a pre-cancerous lesion as long as it doesn't overlook a cancerous one moving into the invasive stage.

Both cancers are relatively slow growing so it is reasoned that detection, if missed the first or second times, will surely be picked up somewhere down the line. Later in the book, we will give our reasons for suggesting that any early detection test should not be trusted more than our own awareness of troubling symptoms. Abnormal bleeding should be a stronger indication of potential cervical cancer than the results of the Pap smear itself.

During the spring of 2000, we tried a new approach that was to openly confront the agency with evidence that its work was shoddy, particularly in the area of screening a sample and communicating results. We were aware of a possible conflict of interest that this put us into; on the one hand, praising the agency for its lead role in overseeing the successful past treatment and, on the other hand, criticizing it for contributing to the problem in the first place.

On a number of occasions, we came agonizingly close to getting an admission from various higher-ups that something had definitely been bungled in the process. As a respected doctor in the community once confided to us, a series of mistakes had unfortunately been made along the way, and people were now scared for their careers to stand up and assume responsibility peradventure they got tagged with everything. Specialist after specialist admitted that there was a problem with how Belle had been treated but, in essence, implied, 'it was always the other

person's fault' or 'we're not willing to comment on someone else's work because it might be considered unethical'.

It would seem that Belle's situation comes down to three fundamental questions. We have answered two already through careful research of the facts. The third remains a mystery until some respected third party renders a judgment. Here they are in terms of their time-sequence:

a. What was Belle eventually diagnosed with in March 1999? She had squamous carcinoma of the cervical and endocervical areas in a Stage 4B development. This staging represented the spreading of the cancer into the pelvic lymph nodes.
b. Could this disease have been prevented from spreading to the extent that it did? On two accounts the answer is an emphatic yes. One, Belle had a regular biannual Pap smear that showed a continual pattern of negative results. After the fact, we were able to ascertain that the agency, in the past, had some serious problems rendering reliable Pap smears before June, l998, because of faulty procedures. Two, the record on cervical cancer is very good if caught early. Survival rates go up enormously when detected and operated on at the 'in situ' stage.
c. Did Belle have cervical cancer before or after the May 1998, Pap smear that was recognized as a false negative by the agency in early 1999? Because the physical evidence had been so badly contaminated in her medical records, a person might conveniently conclude that Belle's cancer was a fast growing one that sprung up only months before it was detected. Therefore, their conclusion would be that the abnormal bleeding she was experiencing was only the result of oncoming menopause. As described later, we know that Belle did not have a rapid onset cancer because she does not fit the age profile or tumor type. Some expert in the field of tumor types and gynecological disorders might try to repudiate this statement. There is testimony to the fact that all the earlier signs such as two questionable rereads of the l994 and l996 samples, the continuous heavy bleeding, and the false negative of May, l998, point to the fact that Belle had cervical cancer earlier rather than later.

We have stretched ourselves to the limit in terms of presenting an unbroken chain of events that take us to mid-2000 in our search for the truth. We have related this narrative to our reader in the same way that it has unfolded to us through our meticulously kept notes. A litany of events that, at the time, made no sense but, upon further review, revealed a pattern of unmistakable cause and effect. The last few weeks have been very quiet in regards to new information surfacing. While we are not prepared to give up our search for the truth, we have begun to concentrate on more immediate concerns, such as the needs and interests of our two sons.

Our younger son graduated from high school in June, 2000, and hoped to enter university in the fall or winter. Our older son continued to work away at his studies to become an accountant. We admired his dogged determination to pursue this very lofty but equally exacting goal. Through all this, both young men have pushed the boundaries a bit in order to get effective results. Before Belle's illness, our home may not have offered an opportunity for independent living. That has all changed over the past year. Before March, 1999, we were a family that lived more for our own private interests rather than common goals. That attitude, while not always harmful in itself, has changed somewhat over the past year to produce a more sensitive group of

individuals who are caring more for each other. All told, we still want to see our children step out and make effective lives for themselves.

This chapter concludes with Belle and I praising God for all His wonderful blessings in our lives. We have dreams that involve our children only in the sense that we desire to see them succeed as God enables them. This requires a lot of letting go and trusting God to protect and provide for them.

Several months after Belle's last treatment saw us coming out of our shell - our shadow land - and begin to socialize again. We took a trip to Ireland in the summer of 2000. During this time, Belle and I were able to visit family and friends and enjoy some private time in Bantry by the seashore. It was the type of getaway that we haven't had for a while where we were able to stretch out and read, sleep and meditate, be oblivious to the world around us and not have to worry about treatments.

We have committed ourselves to going all the way in investigating the causes of Belle's illness, simply because we believe in her cause. We are the most surprised of anyone that this experience is being presently transformed into a book that crystallizes our thoughts into a story that contains controversial issues and practical morals. Up until recently, we had always wanted to write a book but had nothing to motivate us. Now, we have found a suitable subject but are finding it difficult to bring all the information together to do justice to it. Explain that one, if you can! Not every story is publishable but, in order to get to the place where somebody is willing to sit down and read it, it requires a lot of writing about an issue that is of interest to others as well as ourselves. To this end, we encourage anyone who wants to write about their experiences of being suddenly struck down by a major disease, especially one as preventable as cervical cancer, to let the facts speak for themselves. That is how a story emerges out of what looks initially like chaos.

Chapter 8

A Time to Relax and Move on With Our Lives

To act well in the world, one must die within oneself.
Man is not on the earth only to be happy.
He is not there to be simply honest.
He is there to realize great things for humanity
and to surpass the vulgarity in which
the existence of almost all individuals drags on.

- Ernest Renan, 19th Century French theologian

It is a strange experience to shift from an intensive preoccupation with personal medical treatment, in one part of the country, to another considerably less intensive and more diversified family existence, in another, with only a short period of time in which to adjust and recover. In the transition from cancer treatment to resting up to finally going back to work, Belle and I have maintained, virtually, the same drive and motivation that amounts to living each day to the fullest. While the intensity of the battle may wane somewhat because we are removed from the frontlines, the continuation of re-focusing in terms of making sense of the road ahead remains constant.

Admittedly, Belle is out of immediate danger from cancer; however, that reality only begins to allow us to transfer our energy elsewhere to avoid being caught off guard again and to help others come through similar troubles successfully. The transforming and jolting experiences of the two preceding years of Belle's illness might no longer dominate our lives as they once had, simply because we chose to focus on a new area of living. This chapter briefly describes the new forces working in us now to expand our appreciation for what life offers.

A return to our community would serve to remind us that our lives have changed significantly over a year or so. In one sense, there was a less threatening world awaiting our return with all the old familiar landmarks. The same old vitality seemed to be waiting, telling us that there was no time to lose in making adjustments and getting on with life. We take less time to sit around and plan knowing that our futures are really appreciated and cherished when lived in the here and now. Call these compelling forces what you will: family, home, loved ones, work, healing, or simply normalcy, they have become dynamos that push us to invest more of our time wisely in the 21st century.

The year 2000, and hopefully beyond, has become that zone in which Belle and I have started to move on further from our problems, rather than remain stalled in them. The threat of imminent death is receding; the prospect of prolonged discomfort has vanished; and our sense of joy in adventure has gradually returned. We are becoming once again a family that can plan, dream and marvel at God's healing and restorative powers. This does not alter the fact that He might have some other great challenge awaiting us somewhere down the road. Some family member may want to move in another direction hoping to overcome his special set of hurdles.

This chapter looks at where we've gone in our journey to fight cancer in 1999 and beyond. While the cancer was personally Belle's, it quickly became a shared problem for all members of the immediate family. Each of us has a story to tell that might look like this: somewhere back in our distant past, a very dark and sinister force - like a storm cloud - came into our lives and threatened to destroy the security to which we had become accustomed. That crisis has now been weathered and, miracle of all miracles, none of us desires to return to that old sense of false stability where we lived protectively and selfishly in case we lost everything.

The first compelling force in our life is the desire and need to get Belle's story out in whatever form. Belle and I have been very encouraged to realize that our friends, acquaintances and even strangers are more than willing to listen to us relate our experiences. We have had ample occasion to talk to high school classes, to people on the street and to friends in our home or through our church about the dangers of misdiagnosed cervical cancer. While we are not on a mission to save the world from its own indifference, we still want to impress on women especially how vulnerable they are to this awful disease. We are not critical when it comes to wondering why people don't share the same enthusiasm or passion for talking about the threats of cervical cancer to the family as a whole. Such hardships only strike home when they affect somebody's personal life.

A second force has taken over our lives recently; the need to reform and revitalize healthcare in small town Canada. It alarms us to no end to see the decline of sound rural doctoring in this country. The shortage of efficient physicians in the backwaters of society speaks to the fact that the economic base of many of these places, such as where we live, is shrinking. Competent general practitioners, who might ordinarily be inclined to refer a woman for a follow-up treatment by a specialist, are moving away to the big centres in droves. Our town is no exception. We were originally delighted to learn that two of the three doctors responsible for mismanaging Belle's case had folded their joint practice soon after she had gone for treatment and were replaced by more committed family doctors. Since then, these new doctors have openly talked about moving to a bigger community where there are better facilities.

Early detection of any disease - especially cancer - will suffer considerably if there are fewer conscientious practitioners to call on for referrals. This past year has shown us a major difference between those doctors who treat healthcare as a job and those who treat it as a high calling. A local drop-in clinic, as compared to a more family-oriented one, is an example of a fee-for-service delivery that provides only superficial care. The latter model of delivery puts fewer restrictions on how much time a doctor spends with the patient in learning about his or her medical needs. Because of its very nature, the former attempts, in most cases, to push as many people through the door as the billing system will allow. Consequently, names and faces are expendable in the interests of paying off overhead - whatever that is! It is a well-known fact in socialistic medicine that most local doctors do not carry anywhere near the overhead that a dentist would carry.

A prominent gynecologist told us recently that most general practitioners are not trained to recognize gynecological abnormalities such as a cancerous cervix or uterus. It is incumbent on the doctor to develop an interest in the patient's concerns and follow them up to the point of referring them to a specialist. We don't need more doctors in our medical system to work on a fee-for-service in order to prescribe more tests and write more prescriptions. As a lawyer-friend of mine once pointed out, these are so-called professionals who end up killing you or your loved one with too much or too little attention. Communities have to make the supreme effort to attract

doctors who care enough to share their skills that will put the patient's interests first by referring them to specialists who can ascertain the problem and prescribe the ideal treatment.

A third factor has recently surfaced to change our lives. We have now been able to convince a law firm to represent us in a civil action against a number of parties allegedly involved in providing Belle with less than adequate medical attention. To reach that point where both the litigator and the litigant agree is anything but direct. It has taken considerable time on the part of both lawyer and plaintiff to collect documentation, seek professional opinions and examine all potential pitfalls. All kinds of American, British and Canadian journals have been involved in helping us to determine that crucial standard of care; the sources of which are carefully laid out in the back of the book. There still remains the need to obtain the all-important expert witness to testify to long-term effects arising from neglect.

What we have found is a three-fold answer: excessive and abnormal uterine bleeding warrants checking out by the local doctor; unreadable and obscured Pap smears are invalid and should lead to further investigation; and early detection of cervical cancer in an 'in situ' stage can result in an improved prognosis. On all three counts, the medical system failed Belle. A further search came up with a landmark Canadian case where the estate of a Manitoba woman, who had experienced similar neglect, sued and won a substantial award. Recent research papers by eminent scientists in the field suggest that a lot of Pap smear false-negatives are the direct result of poor scrutiny at the lab level. One very obvious fact is that 10% of all women contract advanced cervical cancer shortly after receiving a negative smear result. The inflammatory exudate seen on the slide is the direct result of dead cells and bacterial build-up resulting from a fast-growing carcinoma. Most labs claim they are not equipped to review potentially questionable slides so they take the economic and ethical chance that nothing is wrong because statistics are on their side.

In late October 2000, when lawyers contacted us and confirmed that they finally saw what we saw - reasonable grounds for pursuing an action against four different parties - things began to get interesting. As a result of fairly compelling evidence, they were willing to be retained on a fee-contingency basis. While this was no million dollar suit - as a lawyer once told us - we have the assurance that a very grievous wrong stands to be made right with ample compensation possible for those concerned. Our understanding of this rather litigious term is that our solicitors are to receive between 30% and 40% remuneration for costs and risks if there is a settlement in our favor. Do we feel that this arrangement is high? Yes, but is the standard for the legal profession in compensating lawyers for doing something we could never do by ourselves: represent our own case. We have been told that we are in the hands of a competent firm who only proceed when they believe they have a winnable case. They have a high rate of success based on the fact that they take their time in assessing the case and the clients. There is, however, that caveat that at any time a case can fall through because of the unforeseen.

The only thing that remained to be done was for them to line up their expert witnesses, serve the writ and get the show on the road. Or so we thought! When lawyers talk to lawyers from the other side, cases take some very interesting twists and turns. There is also that real possibility that ours is not the only case on the docket and that we have to bide our time. Belle and I have been handed at least three possible short- to long-term scenarios in which her litigation can transpire; none of which fit neatly into any future calendar or planner. All the expert witnesses have been brought on side and all of the primary and secondary evidence has been marshaled for that definitive moment. Local practitioners, specialists from as far away as California and a couple of local experts in the area of medical standards are available if required. While we wait in

suspended animation for 'the show to begin', there is that realization that there is no going back and yet there doesn't seem to be a great deal of momentum.

During the lull in late 2000 and early 2001 when very little seemed to be happening, we felt the pressing need to keep busy and occupied. A fourth force entered our lives with increasing intensity: the need to get things done just in case there was a switch into high gear. One key priority was to become actively involved in helping our younger son make the transition to college in the fall of 2001. There was also the need to put the final touches to this book. If there was any time left over, it would go into preparing for spring planting in our greenhouse, developing lessons for school, cataloguing all our medical research, completing some interior painting and getting back into a conditioning program that would likely involve running and dieting. A fair plateful, if I may say!

Since the key pieces were already in place, what lay ahead certainly could not be as challenging as what we had faced three years before. Our older son had just finished a very tough accounting program and was looking forward to staying in the city. There is some growing evidence that Eliot, his younger brother, was also considering a move south. As expected, our job as parents was helping him move by smoothing the way.

As for finishing this book, we needed to conclude our legal affairs first. Belle's story cannot come out until all legal issues are resolved as lawyers apparently hate having controversial material out there as they proceed to discovery or trial. This means that after more than seventy-five pages of painstaking writing, there remains an epilogue still to be written. It would be very satisfying to be able to offer our readership the final outcome of our story.

On a more pedestrian level, Belle and I began paying attention to some domestic matters that have been put off for the past couple of years. That included planning what next summer's crop will be in our backyard hothouse. After some debate, it has come down to cucumbers (dill variety), carrots, hot peppers, and a few tomatoes. We took every occasion to get the soil ready by introducing more compost and setting up our bedding plants in advance. While we have never pretended to be 'green thumbs' by any stretch of the imagination, having a garden to turn to - whether flowers or vegetables - is a real solace and tonic in troubled times. Preparing the ground, ordering the seeds, weeding the plants and harvesting the fruit were all essential parts of having our lives normalized.

A fourth force involving strong family ties made itself felt in our lives during this period. We both desired to strengthen those family ties that would both encourage differences and similarities. Belle and I became reconciled to the fact that such an ideal does not mean we will be able to preserve the traditionally tightly-knit home so much as maintain a bond of love and fellowship with our children, even as they move away and begin lives on their own. This has meant the need to stand by each other in trying times, to work out differences and enjoy each other's presence into the bargain without unduly stifling personal freedoms. Maintaining this very fine balance is a challenge at the best times. I am full of energy to have projects and plans completed while Belle is quite often unable to keep up with my frenetic pace because of lingering fatigue problems.

Eliot, on the other hand, is off on a different tangent, working in a local restaurant, taking computer courses, socializing with friends, and planning for college in the Big City. He was obviously looking forward to the day when he finally became independent. Both Belle and I admire that fierce sense of independence in him that is gradually coming to fruition. Where and when we come together in a given day is taken care of in the special moments we get to share

with each other: mealtime, movies, bowling, the 'Tonight Show', walks, shopping, reading and regular telephone calls between places of work.

While my philosophy at this time was been to get fully and passionately involved as a way of blocking out the lingering fears and doubts that frustrate our future, Belle's is less complicated. Her pace was 'steady as she goes', with great attention paid to detail. I have to credit her with an infinitely better ability to problem-solve, simply because she takes the needed time to read the instructions and fine print. Our relationship has always been one of my supplying the requisite energy and inspiration and her providing the necessary wisdom to properly harness it. What a dynamic team!

She put in a very active day, both at the office and at home, but by early evening began to fade because her stamina gave out. Oncologists told her that at least 20% of heavy dose radiation patients experienced end-of-day fatigue for the rest of their lives. For Belle, it becomes a matter of making a positive situation come out of a seeming negative circumstance. Extended rest, in balance with extended periods of work, is a temperament our bodies require to live normal and healthy lives. As I approached fifty, I saw the importance of following her to bed at a more decent time. The extra sleep definitely allowed her to cope with the pressures of the next day.

A fifth force has made itself felt in the form of new information coming our way on groundbreaking cancer treatments. We became aware, over the past while, that a number of pharmaceutical companies in the States are researching the creation of a cancer vaccine as well as creating a potentially better way of reviewing Pap smears with such names as AUTOPAP. While the traditional Pap smear has a respectable track record, there is always room for improvement. With all the concern in the United States and Britain over the rising incidence of false-negatives, these efforts bode well for the future. Unfortunately, any future break-through doesn't offer a ready assurance for the present fight to increase public awareness. A major cancer agency in this country has gone on record as being very worried about sizeable parts of the population - especially minority groups - remaining uninformed as to the benefits of a Pap smear. This continues to be a key argument in this book. Put the money into public education and professional retraining before offering a better technique. As of now - with the exception of a computerized system such as Papnet - there is no better way for combating cervical cancer than personal vigilance and due diligence. As part of the North American scene, we tend to be fixed on solving breast and ovarian cancer at the expense of ignoring the warning signs that cervical cancer could easily make a comeback, given a further decline in medical standards at the local level.

A sixth force in the form of books continued to dominate our lives, even in spite of the lay off. It became my big desire to seek out those books on our shelves that have either been only half read or remained unread. Early morning and late evening would become my favorite times for reading a book that might have as much to say about Joan of Arc as it does about Edward VIII or French viticulture in the l6th century Isle de France or cytotechnology. Blessed with such eclectic tastes, I often figured that I am seeking the elusive pulse of life from the printed page. Maybe it is the answer to a very big question such as why human beings are so slow to learn from their actions. My students are often encouraged to work their way in their reasoning to the most difficult metaphysical question of them all: what caused so-and-so to do what he did? Discovering the motive or showing causation helps explain most of human behavior. If, for one moment, I relinquish this challenge of searching for meaning and truth in people's actions,

including my own, I might easily revert to boredom and discontentment. We know full well that much of life to some may essentially be subject to vanity and distress over never grasping its full meaning. This does not alter the fact that there are many 'big picture' concepts that we need to understand in order to become more confident that living has a purpose, if only to bring happiness to others and perhaps a greater appreciation of the truth.

One such revelation occurred when we did some methodical searching of the Internet for the most current research on cervical cancer. It took me into an area that I had not given much consideration to before: the work of gyneconcology. This is a field that deals with the actual treatment of gynecological disorders in terms of finding the cause and applying the right therapy. These people are not just ordinary gynecologists who might be able to recognize cervical cancer in its most subtle form but are top in their profession because of their capacity to both diagnose and treat. Exploring the official web site for the OBGYN Group brought out a list of California's top twenty gynecologists and some very categorical statements on where mistakes in interpretation and diagnosis could be made by doctors leading up to the critical time of treatment. Up to this time, nobody wanted to tell us what the inflammation and exudate actually signified or why 10% to 20% of women with cervical cancer have a negative Pap smear. It is just a statistic that embarrasses cytopathologists into admitting that there is nothing they can really do to remedy the situation. There is, supposedly, many times when the dreadful triage of 'pus, blood and inflammation' crop up on smears for any number of reasons of which only a small fraction might, upon investigation, reveal invasive cancer. Everyone from the local doctors to the specialists at the agency wanted us to believe that these oversights in Belle's case were accidental and came with the tricky fields of cytopathology and gynecology. The greatest irony in this discovery is that our lawyers, in anticipation of avoiding this stonewalling, have already consulted a specialist from California who might be able to provide an objective assessment of the degree of care available to Belle. The ultimate litmus test of any case is found in the quality of expert testimony a lawyer brings into court. Though we knew this many months ago, we are just catching up with its full impact in terms of realizing what good hands we're in. That is what quite often happens when people limit themselves to thinking within the proverbial box and refrain from reading any more than they have to.

The seventh and final force that compelled Belle and me to learn from our recent past was our simple but profound trust in God. We recognize that there have been lots of challenges to overcome and adjustments to be made during these past few years. None of this would have made sense if God had been left out of the calculus. There is Belle's never-ending battle with fatigue, uncertainties about her future health, our careers, our children's future, our parents' health, my lack of a relationship with my siblings, our role in church affairs, our desire to have our day in court and, finally, our need to get this book published.

The pressure and strain that comes with wanting to get positive results in all or some of these parts of our lives can, in varying degrees, conspire to make a spousal relationship edgy and frustrating. For us, it is simply a case of two partners being unable to row at the same pace because of physical limitations. Only recently did we learn that some of the short-term memory problem that Belle periodically encounters stems initially from an underactive thyroid but has been significantly aggravated by the cancer therapy. As a result of this revelation, I can now appreciate more fully Belle's immaculate organizational skills of retaining critical information in terms of what it once was and still is. This is another perfect illustration of possessing and using skills to overcome problems that we often don't even know we have.

If there is any noticeable flaw in our strategy to keep our heads above water, a quick review might reveal a couple trying to do too much in too short a period of time. Invariably, there are periods of time where abandonment, lassitude, ennui, and even helplessness creep in, and no amount of resolve seems to improve the outlook. God's Word has told us to ask of Him if we lack wisdom or skills on how to work through those tough times of growing anxiety, fatigue, malaise and petty disagreements and to cast our burdens upon Him if they get too great to carry. Aggravations only get worse when you try to get ahead of yourself with quick solutions. When plans don't work out on time like we have come to expect, it might be an indication that our Heavenly Father really controls our time, not ourselves. He has given us lessons on how to be patient and not expect too much too soon, brought us in touch with people who care and also need caring for and endowed us with a fresh desire to stand up for the truth. Even if our story goes all the way to trial, it will not end there. In the interim, many new opportunities have popped up so that any conclusion in this lifetime is not likely. Retirement might be nice for some but, for us in these uncertain times, it isn't worth waiting around for to eventually enjoy if it means losing out in the present. We often feel we are engaged in the lives of others simply for the divine purpose of using those incredible people skills God has equipped us with. These are the capacities to commiserate with others, to plan, to organize, to encourage, counsel, physically help, listen to and, most importantly, keep silent at an appropriate time.

Just recently, for instance, we have begun to look forward to a possible trip along the Alaska Highway this summer: a symbolic journey into completely new territory with all it has to offer in the way of wilderness scenery, tranquility and wide-open spaces. This is something we've talked about doing for a long time but never quite got around to because of other intervening events. As usual, we will plan this holiday to include elements of the known and the unknown. We have never seen Alaska in its natural splendor except through the power of pictures. Our first impressions remain constant about its fabled spots such as the Kenai Peninsula, Liard Crossing, Mt. McKinley National Park, the Inland Passage and the Yukon River seemingly bathed in the brightness of endless sunlight. Such a feeling best summarizes our attitude in attempting to know what we believe is true about a critical situation such as Belle's cancer. We believe in our hearts what we are now ready to see worked out in our lives. A trip to Alaska is very comparable to us heading into an actual court battle with a myriad of facts, experiences and pictures on our side.

As we move through 2003, we have allowed these basic powers to dominate our future outlook. They essentially include our love for God, our family and our fellow humans. They teach us how to grow spiritually and socially by plugging into the big picture and forsaking the perils of self-doubt; to have reason to hope. We admit that we have little control in terms of ordering the events and times that come our way. However, I believe we have found considerable success in handling those moments of hardship and testing so as to obtain the maximum results.

As some wise person once said, "We often can't help the circumstances we find ourselves in, but we sure can have a say as to how they shape our lives for better or worse."

Chapter 9

A Time of Personal (Belle's) Reflections

I had not intended to actually write a chapter about my personal experiences, as I spent a lot of time helping Ian to proofread the book. Then we were advised to delay publishing until after the legal situation was cleared up, so this gave me more time to do my bit. This chapter will be a little difficult for me to write, as I don't usually talk about very personal things. I will mention some points, but only briefly, that are written about in more detail elsewhere in the book.

Where to begin? Perhaps in 1997 when my monthly cycles began to change. I have read books where women have said that they don't want their monthlies to end, but not me. I was looking forward to the time when they would be over. When June went by without a period, I was hoping that this was the beginning of the end. The next few months were more or less regular except for December, 1997, and February, 1998, so things were looking good. Unfortunately, it was the 'lull before the storm'.

Beginning in April, 1998, my monthlies came back with a vengeance. What was going on? Was this normal for perimenopause? I mentioned the heavy bleeding to my doctor who asked if I was having hot flashes yet (which I was not) and that was the end of the conversation. When I had other occasions to visit the doctor, I again mentioned the heavy bleeding but was given no satisfactory answer. There seems to be some confusion as to what is normal bleeding coming into menopause. I did ask one or two other ladies how they were affected and they did admit to heavy bleeding. However, I did not establish for how many months. My bleeding was now lasting for as long as four weeks with many days of heavy flow and very few free days in between cycles.

Many nights I would wake up after three or four hours sleep and lie awake the rest of the night. I had black rings under my eyes due to lack of sleep. Was this all due to menopause? I was tired all the time, and after a day's work had little energy left, but then other people felt the same too.

We went to Hawaii in August, 1998, and we had a great time. Unfortunately, I was unable to participate in many of the activities such as snorkeling on the reef. Swimming had to wait until about the last day when the bleeding eased off enough in the evening to allow me the opportunity. How I would have loved to go in the sea with the rest of my family during those two weeks to cool off from the very hot summer days.

At the end of the summer (1998) a blood test revealed that I was low in iron so the doctor prescribed an iron supplement. How long was this abnormal bleeding going to last? I would give it a year (to April, 1999) and then ask for some better answers.

The bleeding was becoming heavy enough to cause me to go to the bathroom several times at night where I passed large blood clots as well as during the day. Many times I used two pads (for heavy flow) simultaneously so that I wouldn't have to change them every 30 minutes or so. I was also experiencing a lot of mucus in my throat (especially at night) and, at times, it felt close to choking point. Was this another symptom? This began several weeks before treatment but, happily, stopped afterwards.

Early in 1999, during the day or two between the periods when there was no flow, a clear discharge could be seen and, in early March, an odor developed. It was about this time that blood of a lighter colour was seen after intercourse because the tumor on the cervix was disturbed. It was only later that I learned these were the first visible signs of cervical cancer other than the excessive bleeding. Looking back, I wonder if the continual white discharge I had for several years was also a symptom. (That problem also cleared up after treatment.) I am not writing to sensationalize the problem but, hopefully, to make women aware that those seemingly natural occurrences can be early warning signs of the advent of something serious. I had been lacking in energy more than usual for several months but, other than that and the bleeding, there was no pain or any feeling of illness at any time to indicate that anything was wrong.

On March 21, 1999, while taking a shower, I discovered a lump on my right groin. What was this? Would it disappear in a few days? I had come down with a bad cold the week before so by Wednesday I decided to take a day off from work in the hope that it would improve. This was an opportunity to visit the doctor so I made an appointment to have the lump checked out.

The doctor was a locum, and she didn't voice her suspicions when she checked me out but said she wanted me to see a gynecologist. The next morning I got a phone call from the doctor's office to say the appointment was for that afternoon - which was quick work! We (my husband and I) left at lunchtime to travel for two and a half hours to keep the appointment. The gynecologist knew right away that it was cervical cancer because she had seen many before. This had never entered my mind at all. My mother had cancer, (not cervical) but I was expecting at least one of my two older sisters to contract it first. What a shock that I was the first!

Preparations moved fast after that. We were able to enjoy Easter in early April at home. The following weekend we were on our way to a main cancer centre for five weeks of treatment. Ian has written elsewhere in the book about the events of our arrival at the agency, but I want to mention a couple of things here. At the initial meeting with the doctor one question was about swollen legs. My legs were not swollen, but it was only later we realized the significance of that question. Ellen, whom we met at the agency, had cancer so advanced that her legs were permanently swollen. Another question was about weight gain. I know that a person loses weight when the cancer is advanced, but I never thought of it causing an increase. Interestingly enough, I had gained ten pounds in the past year or two in spite of exercising regularly and watching what I ate. Once the treatments got going and side effects (slight nausea even though I was taking nausea pills) kicked in, I didn't feel like doing very much other than to lie around our room. However, Ian was an inspiration and encouragement so we did many enjoyable activities each day.

To receive radiation, I had to have a simulation when they marked key spots on the abdominal area so as to guide the beams to the same spots each time. Four of these were 'tattoo' marks as they remain forever, and others were felt marker that I was not allowed to wash off until treatment was over five weeks later. Every weekday, it was the same routine. We would arrive at the agency, take the elevator to the second floor, walk round to the radiation office, drop off the appointment card, pick up a rather nice blue gown which was kept in a specially marked bag (I would use this same gown until treatment was finished), strip from the waist down, put the gown on and, then, wait to be called. There were lots of magazines in the waiting room to read, but if reading wasn't your thing, there was a basket of wool and needles for some therapeutic knitting. It was interesting to listen to other patients tell their story so striking up a conversation was

another way to occupy the time. I had to drink several glasses of water before treatment so if I needed more, there was a bottle of filtered water here too.

When I was called, I was taken through a hallway into a large and airy room behind the reception office. This was one place where Ian could not accompany me. I would climb onto a bench-like bed, the top of which was then moved backwards under the great radiation machine. Two or three technicians would spend three or four minutes positioning this machine so that the beams lined up with my marks. This also entailed some pushing and pulling on various parts of my body. These first few weeks, I also breathed in a mixture of bottled oxygen and carbon dioxide for four minutes before and during treatment. This was a new treatment used to enlarge the tumor making it more vulnerable to radiation. When everything was set, the technicians turned out the lights and left the room with music as my only company. They were able to see me from the office and also maneuver the machine from there too. First of all, the arm of the machine was slowly moved underneath to my back which was zapped for ten seconds, moved to my right side which was zapped for ten seconds, and the same for the left side and front. During this time I had to lie perfectly still. There was a possibility of developing burns from the radiation so I was told to use cornstarch - yes cornstarch - instead of talcum powder. I faithfully dusted my back and abdomen with cornstarch each day only to discover burns developing in the creases on the inner thighs. Fortunately, it was no worse than mild sunburn. The actual radiation was only seconds long so we had practically the whole day to ourselves except for about an hour to travel to the Cancer Agency, prepare for and receive treatment. (Treatments were five days a week so we had the weekends completely free.) Sometimes they were running late, so I didn't always receive treatment at the allotted time thus taking longer than usual.

Another experiment the cancer agency staff did each week was to take me to another room where I breathed in the same mixture mentioned above for about half an hour with an electrode attached to my arm to monitor my oxygen intake. The doctor saw the results on a computer screen. This was painless but rather long for lying still and left me with a dry mouth.

Chemotherapy was prescribed for each Monday of the five weeks. When we were informed of what this entailed, we were reassured that cisplatin caused a little thinning but not complete hair loss. This was happy news but, on the other hand, I would have been interested to see how my hair would have grown out again - perhaps in curls instead of straight and, maybe, even a different colour. Chemotherapy would last as long as five hours for each session. First of all, I had to go to the lab at 7:30 a.m. or 8:00 a.m. for some blood work to make sure that everything was looking good. The samples were sent over to the local hospital soon after, and the results were on the computer in the agency about an hour later in time for the chemotherapy appointment. I had the luxury of lying back in a large recliner with a blanket thrown over me for warmth. I could read, talk or sleep if I wanted, but there was too much going on to sleep. As I was hooked up to an I.V. during this time, Ian would bring lunch up from the Clinic cafeteria. A saline solution was administered for the first two hours to flush out my kidneys. The next hour was chemotherapy and the last two hours the saline solution again. After the first couple of hours, there was a need to go to the bathroom several times. I would gather up all my paraphernalia and head to the bathroom in the corner of the room. It was rather awkward with the I.V. needle in the back of my right hand.

As well as nausea, my taste buds were not acting normally so it was difficult to drink liquids, without feeling nauseated, except for orange juice. I soon learned that citrus fruits were a no-no as I paid for it the next day. It wasn't just slight nausea but unbearable nausea. We met Ian's

parents for supper that same evening, but I could only watch as they dined on English fish and chips. In addition, I also developed some mouth sores, as a side effect, at the end of the chemotherapy session.

In the fourth week of treatment, it was decided to give me internal treatment to really 'hit' the tumor. This entailed a trip to the O.R. where I received an anaesthetic for insertion of the tubes. How strange to have three steel tubes in such a position for approximately sixteen hours! I wasn't allowed to move without the nurse's help. This was done every two hours so I didn't get much sleep as it was an overnight event. What a weird feeling to be immobile and cut off from nearly everyone else. No visitors were allowed except when the nurse came in, and the radiation unit was turned off for a few minutes. Who would visit during nighttime anyway except a devoted and loving husband? It was possible to receive and make telephone calls but, again, who is going to use the telephone when they should be asleep? There were two beds in this special room so I had company the first time. The following week, during the second internal treatment, I had the room to myself. I was wondering why my throat was hurting and learned that a tube had been inserted while they were preparing me for this treatment. I am glad that I was out cold as I hate the thought of it being done while conscious because I would be sure to be sick.

When the radiation tubes were being removed, I was fully conscious. There was an enormous amount of wadding to take out. The purpose of this wadding was to keep the tubes in place so that the treatment would be most effective. The first time, the removal went very smoothly, but there was some pain the second time. Thankfully, not as much as the other patient who had a lot of pain as it was her third internal treatment.

There was only one more external radiation treatment to go, and as we wanted to start for home as soon as possible, I decided to take a shower at the clinic before leaving. I had no sooner stepped out of the shower when I started to shiver and just about passed out. Fortunately, Ian was close by and was able to call for help. I was taken back to bed and covered with comfortingly warm blankets to help control the shaking. Was this an adverse side effect of the treatment and what did it mean? Apparently, this was not a common occurrence. It took quite a while (two to three hours) for this shaking to pass but then I was fine.

It was good to be going home after an absence of almost six weeks. Recuperation would take six to eight weeks and then it was back for a radical hysterectomy.

It was during those weeks of treatment that the Nicoll's case was aired on TV. Her problem was so similar to mine that Ian decided to make inquiries at a lawyer's office. To cut a long story short, we presented our case, and they decided to take it on. Ian was tireless in looking on the Internet for lots of relevant information and sending it on to the lawyers. He spent hours, days and weeks seeking out the protocol for Pap smear tests and cases that had already gone through the courts. This could be rather scary especially if I have to testify in court. I am a person of few words and find it difficult to speak in front of people. Perhaps it will be settled 'out of court'. That would be great.

The time passed quickly and soon we were on the road again. We did not go to the Cancer Clinic this time but to a regular hospital. The Doctor doing the surgery was well known to us by now as she also did a lot of work at the Cancer Clinic. She had answered a lot of our questions and helped to set our minds at rest. I was not looking forward to this surgery but, surely, there would be some positive things about it like loosing weight with all those organs coming out and a flatter tummy. It couldn't have been further from the truth. Not only did I not lose weight, but my tummy is like a roller coaster. Well, not exactly, but it is an unusual shape! Surgery was on a

Thursday and we were able to leave on Sunday. There were another six to eight weeks of recuperation. As I wasn't allowed to drive during this time, Ian had to do all the driving home of 700 miles.

Now we waited for the pathology report to find out if the cancer had spread further. After a few weeks, the results came in, and one ovary had been infected. It was suggested that I have a further five weeks of radiation treatment higher up on the abdomen to make sure of catching it all. We decided that it would be best to follow through rather than, perhaps, regret later on not doing it.

Ian willingly arranged to take another five weeks off work in order to go with me. It was quite a challenge to persuade his employers to let him go but he managed it. In mid-September we set out again. I was hoping, and was led to believe, that there would be no side effects this time but, once again, I had nausea. However, we did not let this stop us from getting out and about. The weather stayed glorious right up until the day we left on November 5 which turned out to be seven weeks later as the treatments did not begin as soon as we arrived. With another six to eight weeks to recuperate, I did not go back to work till the New Year (January 2000). It was nine months since my last day of work. So much for reassuring my contemporaries back in March that I would return to work in a month!

When all the treatments were over, I discovered that there were some lasting side effects. I bump into doors and walls which, sometimes, causes bruising. My problem is poor depth perception that prevents me from realizing that objects are closer than they appear. I began dropping items for no apparent reason. There are times when I just can't seem to hold things firmly in my hands. Some of my memory cells were killed with treatment so now there are three things going against me. What with the treatment, my 'age' and, as I learned just recently, thyroid problems (which I have had for a good many years) also causing memory loss, I find it more and more difficult to remember things that happened or was said recently.

Follow-up examinations were in four-monthly periods to begin with. How confusing that the first Pap smear, taken by my local doctor, came back as mild squamous carcinoma. What was going on? Didn't the technologists know that I no longer had a cervix? This result had taken so long to come in that, in the meantime, I had an appointment with a visiting gynecologist. He had taken a biopsy and the result was clear. What a relief! It was rather depressing to learn from this gynecologist that if anything did reappear there was no further treatment available. The only reason for these follow-ups was, apparently, for my peace of mind.

What peace of mind? Is this a lump that I have discovered during breast self-examination? (Our friend, Jane, mentioned earlier, had breast cancer but, fortunately, for me it wasn't this time.) What is the cause of this headache and cracking in my head when I yawn? (Several people we know have developed brain tumors recently.) Is there something significant about tingling feet and an itchy thumb? (I had an itchy thumb for quite some time before diagnosis, and then it stopped after treatment until eighteen months later when it came back again. Is this an unknown symptom of cancer?) Sometimes my swallowing reflex action doesn't always kick in, giving me a momentary feeling of being unable to breathe. Fortunately, this state soon passes, and I can swallow and breathe again normally. Why do I still feel so tired and depleted in energy even now? At the time of writing this chapter, why have I had diarrhea on an average of once a month (22 times) since the beginning of my second treatment, nearly always accompanied with nausea and six times with vomiting?

If all I had to depend on were doctors, surgeons and specialists, the future would be very bleak indeed. I could be forever worried about every little ache and pain developing into some kind of cancer. However, my trust is in my Heavenly Father who is watching over me whatever comes my way. He gives strength, reassurance and hope for the future here and in eternity.

PART TWO

The Disease and Its Ramifications

Chapter 10

How Preventable is Invasive Cervical Cancer?

"What can I know, nothing for sure.
What ought I to do? Try not to hurt anyone.
What may I hope for?
For the best (but it won't make any difference).
There, he said, that's that sorted out."

- William Boyd, Brazzaville Beach

1. What is Cervical Cancer?

When looking at cervical cancer for the first time, like we had in 1998, a number of things should strike us as being very unique about this disease which is classified as one of a number of gynecological cancers. One, its origin can be traced to the Human Papilloma Virus (HPV - nearly twenty strains from the herpes family are known to exist) as its main cause.[1] The literature available on this subject makes no mention of an unhealthy lifestyle or heredity as contributing causes to this disease. Two, it has an unusually long growth period of years before it becomes full-blown or invasive in nature.[2] On average, the incubating stage is three to five years. Three, it shows identifiable or visible symptoms only through a Pap smear in its early or 'in situ' stage before it becomes invasive.[3] Some women have not been aware of its presence until it reaches the invasive state because of ineffective Pap smear tests or no testing at all. Four, it has a very identifiable course through the lymph canals or veins as it spreads outside the pelvic cone. All of these characteristics, taken together, suggest an insidious process that doesn't show up as a life-threatening illness until well into the latter stages. Once it breaks out, it travels very fast through the body's lymph system and has the potential of being deadly within a year.

Many of our friends had great difficulty in coming to grips with the fact that Belle had advanced cervical cancer because she looked so well. All her vital signs and her latest wellness examinations over the past number of years showed that everything was looking fine. In hindsight, all this suggested was a certain unwarranted optimism arising from superficial treatment local doctors had been giving her for a hypoactive thyroid and anemia and cytotechnicians in reading her Pap smears. There is evidence that her Pap smears had some question marks as far back as l994.

Cervical cancer, in its early or 'in situ' stage, is so subtle that the HPV (Human Papilloma Virus) attacks the surface cells in a most inconspicuous and integrated fashion. The initial encounter might simply be a superficial rash or infection that clears up as quickly as it comes. When the virus gains a foothold, it first becomes part of the DNA chain that surrounds the nucleus of the healthy cell. Eventually, it takes over the reproductive capacity of the cell by releasing its own HPV protein (E6 and E7) and mutating the crucial P53 gene that controls cell development.[4] Certain strains of the HPV, namely 16 and 18, have been shown to be more

prevalent in cervical cancer. It is believed that these are the ones that have the most aggressive capacity to mutate cervical cells.

Since it starts in the surface area (epithelium) where the cells are not as soft as the underlying squamous (columnar) ones, it progresses literally layer by layer (see glossary). As these layers build, a tumor will eventually form years later in the area of the infection. The Pap smear test takes a scraping of surface tissue to see if it is developing any cancerous lesions or abnormalities. Glandular tumors, which are normally more aggressive, can form further up in the endocervical canal. If not caught early with an endocervical test, they will lead to a rapid, onset cancer.[5] Fortunately, it would appear that this was not Belle's situation. Hers had progressed from the localized stage to an invasive stage by metastasizing within the pelvic wall and in a secondary inginual node. It was that latter development in the form of a swollen and infected gland - an exceedingly rare situation - which alerted her to the fact that there was something significantly wrong. Normally, in the advanced stages (3 to 4b), cervical cancer breaks out from the parametrium and engages the para-aortic lymph nodes outside the pelvic wall.[6] By that time, the window of opportunity for treatment has, unfortunately, closed and palliative care remains the only viable option.

2. Who stands to get cervical cancer?

Some Perspectives on Cervical Cancer:

There is a somewhat half-baked theory going around which attempts to explain the origin and development of many cancers. It is thought that the human body is being destroyed by the consumption of toxins that rob it of its valuable supply of vitamins and nutrients. The only simple answer, according to these experts, is to detoxify the body through the introduction of enzymes that lead in this process.[7] This over-simplified theory of rather complex processes, such as the functions of human organs, considers that many cancers have the same origin and that they respond in the same way to treatment. There are some studies that show that certain enzymes might trigger cancer. While there might be some truth to the notion that our bodies need to be protected against ingesting dangerous chemicals, there is not a lot of clinical proof that detoxification cures cancer. What cures cancer, in a high percentage of cases, is a proven, radical process that attacks and destroys cancerous cells and prevents them from reproducing. Radiation and chemotherapy (check glossary) fit the bill here. There is a pill just recently released by the FDA in the United States that has significant knockout power to destroy the cancer cells and leave the healthy ones alone.

Another angle as to why we may become vulnerable to cancer cells suggests that we all have rogue cells constantly invading our bodies. They wait to break into cells when the first breach in our natural immune system occurs through sickness, toxic buildup, or infection. There is some evidence that would ascribe this breakdown in the human immune system to the ever-increasing presence of bad or unresolved stress in our lives. The reason why these cells are not detected early enough is because they have such an ingenuous way of disguising themselves through reforming and hiding in various body organs and tissues. This is a very convenient interpretation of events for those who advocate the importance of keeping the immune system in its very best form. A person is encouraged to take a regular dose of vitamins and minerals such as B-17 (laetrile) which are intended to bolster the body's natural defenses and ward off infections.[8]

This idea of toxins just waiting to take over the human body might be challenging to toxicologists in the study of why certain toxins may have mutative or cancerous qualities. However, it does not begin to explain why some people are more susceptible than others to cancer and why certain cancers do not have a toxic origin. While there is always a suspicion that toxic buildup in the body (whatever that is) is a primary agent of cancer, there is no known link at all between gynecological cancer and toxins in the body, including nicotine. It is obvious that Belle's immune system had to be weakened in order for the HPV to take hold, but the explanation for this could be as simple as explaining why many of us catch the flu or the common cold.

Why do certain strains of the Human Papilloma Virus have deleterious effects on the cervix (neck of the womb) while others are easily neutralized?[9] Why do most (70%) of the neoplasia (the early stages of HPV presence in the cells) found in Pap smear tests never become pre-cancerous? Does a typical candidate for cervical cancer have a certain profile that includes a higher than normal state of immune deficiency, i.e. the P53 genetic factor that is susceptible to mutation by viruses?[10] The answer may lie in the mystery of the human gene which makes some women vulnerable to attack while others are immune. Most of the literature seems to suggest that up to 70% of women contracting the HPV will not have it develop into a dysplasia or lesions leading to cancerous growth. There is enough evidence to prove that the Papilloma Virus invades through normal sexual contact and converts healthy epithelium cells (which line the intercavity region) and squamous cells (which are the predominant scaly cells of the epithelium) to cancerous ones.

While cervical cancer effects mostly poorer class women, it shows little or no respect for people whatever their status in life if the rules of early detection, effective testing and treatment, good health care or healthy living are not practiced. There are some studies that show interesting connections within families - including twins and siblings - where cancer has taken hold in terms of a certain inherited gene. Cervical cancer is not one of those situations.

While there is research supporting a definite link between the P53 gene (which controls the reproduction of cells) and the proper working of the body's immune system, that is not the issue. The real problem lies in the capacity of the HPV-16 and -18 to insert its own protein into the cell's DNA (Deoxyribonucleic Acid) and take over its reproduction.[11] As this problem is studied further, it might be learned that certain women have a disposition to this and need to be vaccinated against it. Genetic testing is already being developed in terms of producing a vaccine for the next decade to protect against this predisposition.

Until more is known in this field, the fact that a woman may or may not have a certain resilience to HPV-16, HPV-18 or others is not as significant in fighting cervical cancer as being in good health, having regular Pap smears, having good health care and practicing monogamy. In the case of cervical cancer, 70% to 80% of mild atypia cases (pre-cancerous condition) reverse themselves and disappear. Studies have shown that the size of the tumor, the state of health, the time between surgery and radiation, and the age of the person have some bearing in terms of predicting recovery.[12] In Belle's case, her prehistory involved her mother surviving two cancer operations on the colon and one on a breast. While we might think that she possessed a special resilience to cancers, scientists have now been able to draw a tentative connection, through genetic testing, between children and parents in terms of inheriting a capacity to survive cancer.[13] Genetic testing has the potential to be used in two different ways: early detection to determine the capacity to contract the disease or the ability to resist it. Unfortunately for Belle, there was

no such test available for cervical cancer although research is working on developing one. All the emphasis in the past four decades has been on the effective use of the Pap smear to bring about early detection leading to a cure, while outright prevention of it hasn't gone anywhere. We believe that the Pap smear still has too great a margin of error to be taken seriously as the last word in saving women's lives from invasive cervical cancer. Having said that, it is still the best method available for providing early detection. Something else has to be developed to ensure that women can have better protection against the ravages of this disease, and the answer might lie in developing a vaccine or an adjunct test that pinpoints questionable slides. Other recommendations lie along the line of promoting better training for cytotechnicians who are the front-line viewers of the slides.

More important than the above speculation is the fact that Belle was in undoubtedly good health other than the cervical cancer that had likely remained localized for several years. She entered treatment last April, l999, in serious trouble but responded favorably to the concurrent use of radiation and cisplatin (chemotherapy). This was likely due, in part, to her being in relatively good health and responding well to preliminary tests. An oncologist told us after the treatments had finally finished that she was not sure during those first few critical weeks if Belle was going to respond well or not.

A Japanese report published recently in the British Journal of Cancer, while inconclusive, considers an interesting connection between the genetic mutations in Chromosome 17 of subjects who have invasive cervical cancer and extremely large squamous carcinomas.[14] This, coupled with the recent research that pinpoints the Papilloma as the main culprit in the excessive production of protein in the cell, might suggest a major breakthrough for curing cervical cancer and could likely come in the area of discovering and producing a vaccine. In recent articles in Time Magazine and Nature Medicine Vaccine Supplement on cancer vaccines, attention was given to the fact that finding a vaccine to suppress the various types of HPV is difficult. In many cases, the HPV expresses the ability to form new strains as part of its defense mechanism to create tolerances.[15]

2. What does it mean to have cervical cancer?

In the case of Belle's cancer, over the period she contracted it, there was a fairly rapid growth of a carcinoma that formed in the endocervical region amounting to around six centimeters in width. Her lifestyle is monogamous, modest and healthy, to say the least, which puts her in the low risk group for catching it in the first place. Oncologists know that this kind of cancer is more aggressive in some women than others simply by studying the various sizes of tumors in terms of stage of development. For Belle, the literature released by the cancer agency placed her in the middle stage or resolution based on the facts that it had begun to spread, produced excessive bleeding and a clear vaginal discharge. In other words, the cancer was still within sight and would possibly still respond to radiation and chemotherapy.

It is quite likely that Belle had 'in situ' cancer in the intraepithelial tissue for several years before her last Pap smear test. When the HPV finally surfaced as a tumor, it was at the invasive stage between stages 1 and 4. The drastic complications - few of which Belle had - potentially involve everything from blockage of the urethra (the passageway carrying urine from the kidneys to the bladder) and ultimately uremia (bladder poisoning) caused by an unchecked cervical

carcinoma. In Belle's case, the disease metastasized in the lymph node (inguinal) in her right groin as the only sign that it had moved into an invasive stage out of an 'in situ' one.

For some strange reason, local doctors had not picked up on the significance of the heavy and uninterrupted bleeding but had dismissed it as peri-menopausal bleeding associated with the arrival of menopause. The basic lesson learned here was that cervical cancer might affect any woman up to and beyond menopause. Pre-menopause is an extremely dangerous period because the heavy bleeding can often be confused for irregular monthly flows. The drop in estrogen levels can also contribute to endometrial cancer in the uterus.

The greatest risks come from cases where there is a history of multiple sex partners, heavy smoking or no record of Pap smears. Yet, why do healthy women, such as Belle and others, get this disease when they don't even qualify for any of the above categories? Perhaps, it was the second-hand smoke that Belle breathed in for thirteen years at her work place. Also, it might just come down to many women, like Belle, doing all the traditionally right things such as having regular Pap smears but not thinking to challenge their doctors to help them be on top of potential trouble spots. That is one of the issues this book attempts to address. In an objective fashion, we discuss those potential trouble spots and allow the readers to draw their own conclusions.

A lot of faith has been put on the credibility of the Pap smear, and recent statistics prove its reliability beyond a shadow of a doubt if administered effectively and analyzed properly. Since there is a dramatic increase in women entering the work force this decade, as professionals and laborers, we feel that this is a group which is most vulnerable in overlooking the salient signs of heavy bleeding and viral and yeast infections in the genital region. We know of women in this category who have not had a Pap smear in the last five years. This is the group (35 to 50 years of age) that would think nothing of trusting their local doctor and not proceeding to seek a second opinion if the warning signs existed. Yet, there are many professional women who, because of the time constraints of their jobs, might be lackadaisical in getting things checked out.

4. Twenty Facts about Cervical Cancer

Here is a collection of fairly verifiable facts that can make a difference in providing early diagnosis and prevention. Most of these are gleaned from reading a wide assortment of pamphlets and brochures. We will attempt to give proper credit for each piece of information where possible:

a. Most cervical cancer begins on the surface or epithelial tissue around or above the cervix (the neck of the womb as it protrudes slightly into the vagina) when a HPV attaches itself to a cell wall.
b. Most cervical abnormalities in a dyskariosis (mild abnormalities that should be investigated if persistent) or later in a mild dysplasia or pre-lesion are early warning signs that cancer might develop. Most 'in situ' cancer, where the cancer cells are identifiable but have not amassed to form a tumor, has a curative rate of l00%. It is when it becomes a tumor or hyperplasia that the odds of survival drop from 80% down to 10% depending on the stage. This finding came from the BCCA (British Columbia Cancer Agency) draft copies of its present protocol and other pamphlets given to us when Belle began her treatment.

c. Most cervical cancer takes considerable time to develop, and most early abnormal cell growth never advances to become cancerous except in 30% of women.
d. The Pap smear test (discussed in other chapters) is still the best, least invasive way to determine if a pre-cancer infection has occurred. New techniques and equipment are being recommended in terms of obtaining a more valid sample. These involve electronic scanning, DNA testing and the use of different kinds of spatulas to reach otherwise inaccessible areas.
e. Cervical cancer is one of the easiest cancers to control and treat mainly because it is slow to develop and has a distinct path of development and symptoms of revelation. Why it is such a serious and almost epidemic problem in developing countries is that many women, due to a low standard of literacy, widespread traditional beliefs and taboos, are not aware of the dangers and likely do not have access to sound medical diagnosis.
f. Cytotechnicians (lab workers who analyze Pap smears) have been known to misread or misdiagnose smears because of the difficulty in viewing some cell development. A number of cases have arisen where three tests in a row, over four years, have yielded false-negative results. There is a greater incidence of poor sampling and misreading of smears at the screening stage than is first admitted. We would personally like to see an outside auditing of all screening facilities as a means of establishing an effective standard. According to the health writer of a newspaper, a major overhaul of the agency's screening protocol occurred in June, l998, in which certain checks and recommendations were put in place to prevent slip-ups and failures. If the ongoing in-house checking concerning Belle's Pap smears is anything to go by, this agency has some distance to go before getting a system that works for the patient. Never look at a cancer agency as being infallible because of the great preponderance of technical expertise at their disposal. Under the best of circumstances, reading a Pap smear is something of a technical challenge when it comes to identifying the various stages of irregular cell growth.
g. The average time for reading a Pap smear in the lab is less than five minutes (source: Standard of Care newsletter). Some sources regard this mill-like process to be nothing short of a national scandal especially when it is done manually without the aid of an electronic scanner.
h. Once the cancer reaches the invasive stage in terms of affecting the squamous (below surface) cells, it grows rapidly in size and begins to move to other parts of the pelvic area.
i. The Papilloma Virus is considered to be the main culprit in causing cervical cancer. DNA testing shows the unequivocal presence of the HPV compromised DNA in many of the Pap smear samples analyzed in large studies in the United States. This is a Virus that is inclusive of all women between 20 and 70 years of age. There are virtually no early signs of pre-cervical cancer except the presence of itchiness from a viral infection. Once again, the Pap smear, colposcopy and an internal examination are the sole means that allows this to be checked out. Belle, supposedly, had three negative results in a row leading up to her fateful discovery in March of l999, with no other check other than her annual physical. A further three reviews of these smears show a shocking discrepancy of everything from pre-malignancy to heavy bleeding to acute inflammation.
j. The heavy, nonstop bleeding in the invasive stages, is due to the impact of the tumor as it destroys surface blood cells. Sexual intercourse only irritates an already inflamed situation further by exfoliating or shedding cancerous cells on the surface.

k. The test results always go back to the family physician. Most doctors will convey the results of the Pap smear test to the patient through a phone call from his receptionist. It is incumbent on the patient to ask to see that transcript and take up with the doctor any concerns she might have about the interpretation of results. Our trust in the local doctor was so automatic that Belle never saw the transcript until she had finished her treatment cycle long after the original diagnosis.

l. There are a number of clinical studies on cervical cancer that can be looked at on the Web (check the bibliography for research on the Internet). Most of them are for recurring cervical cancer and deal with adjuvant formats that show little promise. The incidence of recurring cervical cancer is generally much higher among those who had only one kind of treatment in the earlier stages (chemotherapy, or radiation, or carbon dioxide therapy), without the combined benefit of radiation, chemotherapy and surgery.

m. The incidence of rapid-onset cervical cancer is higher among young women (reported within ten years of first becoming sexually active) than their middle-aged counterparts. This would explain why some women, who have regular negative Pap smears on a biannual basis, suddenly seem to contract the disease. It might also be due, in large part, to the presence of an adenocarcinoma (glandular or soft tissue cancer generally found inside the cervical canal) which is infinitely more aggressive than the squamous carcinoma and more difficult to get at.

n. CAT scans and MRI's (Magnetic Resonance Imaging) are effective in detecting the spread of cervical cancer in terms of being able to pick up colonies or metastasis that form throughout the lymph system. This technology is not helpful, however, in picking up micro-sized cells that might be hiding somewhere in the body after treatment. Don't expect to get a MRI as proof that the treatment has been effective. Doctors have told us that the resolution of a MRI is not strong enough to distinguish between existing lymph nodes and potential cancer colonies. Besides, there are only half a dozen MRI units available in our province and most of them are booked solid for the next year or so. Belle received a CAT scan at the outset to see if any cancer had established itself outside the pelvic cone but none when the treatment was finished.

o. The incidence of cervical cancer has dropped significantly over the last twenty years because of the attention given to early detection. While statistics from Health Canada and other organizations bear this out, a new generation has arisen that doesn't appreciate the seriousness of having a Pap smear on a regular basis and being proactive about its results. Also, visible minority groups such as aboriginal women are not responding well to the advice of getting regular Pap smears.

p. The main thrust of any genetic research being presently looked at is to find a means by which the cell's immune system can successfully fight off any antigens before they mutate it. Its biggest obstacles to date are the enormity of the task and knowing what the side effects could possibly be. In this whole process, viruses, in the form of refitted viruses, carry the replacement genes to the damaged cells. Another obstacle is the fact that there are many mutations to the HPV waiting in the wings.

q. MRI technology has been found useful in determining the size of the carcinoma within the pelvic wall in terms of gauging the amount of radiotherapy needed to shrink the tumor. It still has not advanced far enough to pick up the real microscopic forms of cancer that might be hiding in the body.

r. In two British studies done on the quality of information available to cancer patients, it was generally thought (80% of respondents) that there should be no limit to what should be disclosed. If Belle and I had been given access to what was readily available on cervical cancer, I am pretty sure that we wouldn't be writing this book now. It is regrettable that our doctor did not take the time to discuss with us the inherent risks of cervical cancer in middle-aged women. Maybe, it was a case of him not knowing enough to feel confident to alert Belle as to the possibilities of this disease.

s. It has been well researched that the larger the tumor the less chance of survival beyond five years. This is due in large part to the fact that the body can only endure so much toxicity from radioactivity and, consequently, large tumors don't reduce very well. A very large tumor usually implies that the cancer has spread to other parts of the pelvic region or the body at large. In Belle's case, the primary tumor doubled in size to 6.5 centimeters in the space of three weeks. Literature shows that cervical tumors, when they reach a certain size, have a tendency to double in size over a very short period of time.[16]

t. Never accept a Pap smear that is obscured by blood or exudate (mucus build-up). According to Dr. Bob Uthman, smears of this kind can be cleaned up with regular 'detergent' and made very presentable. Other doctors have told us that this procedure doesn't work, so there is no point in using a contaminated sample, because it will never be improved enough to yield acceptable results. The Cancer Agency actually recommends a repeat of such a smear, though it has to be totally obscured before that recommendation is made. In Belle's case, the agency classified the smear as a negative, even though it was impossible to read. If Belle's experiences with cervical cancer speak for anything, it should remind everyone how vulnerable we are as humans when it comes to fighting off disease. We should make a very big point of recommending that all women receive annual - not biannual - smear tests and pelvic checks as a means of monitoring their health. Any gynecological disorder - regardless of how insignificant - should be investigated. Persistent itching in the vulva area is definitely one of the precursors to dysplasia of the cervix. Heavy and irregular bleeding is another overt factor that should set off all kinds of alarms. Ladies, keep a regular record of your menstrual cycle because, if properly maintained, it should be able to show unusual trends. Finally, only consult with a doctor who cares for, and shows some understanding of, the problem at hand and is willing to refer his patient to a specialist right away.

Footnotes:

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Chapter 11

Family Ties, History, Environment and Attitude

"For what matters above all is the attitude we take toward suffering, the attitude we take our suffering upon ourselves"

- Viktor Frankl, Man's Search for Meaning

1. The Reason for the Search

Where does one begin to make sense of a disease that has struck down a loved one in the prime of life? A disease that is, by all accounts, supposed to be on a steady decline especially for women who receive an annual Pap smear! There are no simple answers to pressing questions that demand immediate attention. How did this happen, and could it really have been prevented or, at least, stopped before it advanced so far? These were the persistent questions that continued to haunt us long after we first learned of Belle's illness and tried to piece the clues together. It is comparable to taking an indefinite time to solve a very difficult crossword or cryptic puzzle that commands one to focus all on a few obscure words.

Careful examination of the medical facts in Chapter 10 has already told us essentially what cervical cancer is about and how it accessed Belle's body. Now we have to examine, for what it's worth, the possibility that some more distant and extraneous factors such as heredity, lifestyle and living environment may have had an impact on the disease getting started. This is a chapter largely devoted to the important academic exercise of investigating possible connections between external and internal forces in Belle's distant past; all for the purpose of satisfying our innate curiosity that something other than personal neglect might have caused the problem.

We would like to know if this disease could have been prevented if the right conditions had existed. Maybe there are some clues hanging around in our distant pasts that will explain why Belle has been victimized by a cancer that was thought to be virtually brought under control in most sectors of North America. Is cervical cancer a preventable or controllable disease? To this end, we will look at the importance of family ties, personal history and environment as to how they impacted Belle's life to the point where she contracted cancer.

2. Family Ties

Examining who we are as individuals in relation to our historical families might eventually provide a vital link to determining the origin of Belle's disease. We know full well that, at present, there is no strong hereditary connection between parents and children in regards to passing on cervical cancer. D. Easton, in an editorial for PERGAMON titled 'Familial Risks of Cancer' states:

'It is also possible that, by studying the interactions between genetic susceptibility and environmental risk factors, it may be possible to unravel some of the complexities of environmental causes of cancer as well.'[1]

On the surface, there are some small trouble spots in our respective family backgrounds that might suggest a predisposition to or history of cancer. Both my father and Belle's mother contracted different forms of cancer between early middle age and early retirement years. While bone cancer (multiple-myloma) in my dad could easily be attributed to working with environmental hazards such as a continuous contact with creosote and other wood preservatives in his workshop, Belle's mother's colon cancer probably occurred from her eating a heavy fat diet lacking in fiber. Genetically, the gene that carries the bone cancer code may be passed on between parent and male child; in my case, there is a one in three chance of having the same affliction as my father. Some scientists might suggest - though not necessarily - that Belle's present cancer indicates a genetic capacity (a mutative P53 gene) for cervical cancer, making her part of that 20% to 30% bracket in which the virus (HPV) takes hold and eventually becomes a tumor.

To counter this argument, we only have to see the distinct possibility that the resilience in Belle's mother, to survive three serious cancer operations in the colon and breast in the l960's and '70's, might have been passed on to her daughter. If Belle's mother survived because of factors called will power and an unshakeable trust in God, shouldn't Belle stand the same chance? Certain cancers are more genetically inheritable than others are such as liver, breast, and certain kinds of leukemia. The fact that neither Belle nor her mother had any of these cancers in common does not lessen the importance of odds of survival being passed on between mother and daughter.

What is most peculiar about these chances is that they are only some researcher's intelligent estimation - based on one or two factors drawn from some limited raw data from a clinical study - of anyone's chances to live the next fifteen years without relapsing. One might call it clutching at straws or grasping at thin air, as one is about to fall off a cliff. What are the chances that one of those straws actually turned out to be a sizeable root or the free-fall was stopped by a ledge or jutting tree? The odds for us as Christians would be nothing short of miraculous. Surviving anything as catastrophic as cancer, especially when it is in the final stages, is providential. It is these terribly imprecise statistical odds and averages that we humans often clutch at as a security blanket in trying to reassure ourselves of invulnerability and a relatively risk-free existence. The only statistic that might have any relevance here is that Pap smear tests can and do save women's lives if used early, often enough and competently. Anything after that, it is strictly in God's hands as to how He directs and uses very skilled doctors to bring about recovery.

Healthy living, good genes, mental toughness, good diet and regular checkups can become delusions that tend to deny our mortality. The next five years or five seconds or whatever God chooses to give us are certainly not going to be spent looking anxiously over our shoulders to determine if we've beaten the odds. Cancer, based on what we don't yet know about the human gene, has just as great a chance to strike anybody whatever their family history. For example, I might be the one out of all my siblings who gets bone cancer, and there is nothing medically that will alter that course. Simply put, there are no guarantees that we can avoid cancer, with or against certain odds. Time is the only proof that one has pulled through. Ironically enough, there was a significantly greater chance that I'd contract cancer through my dad than Belle would through her mother. Yet, wonder of wonders, she's the one who got it, and I'm left wondering

when or if my turn will come. Maybe, the more significant factors worth considering are not the odds of catching cancer but fighting and overcoming it.

3. A Healthy Lifestyle

Another dimension of our personal health profile that figures in this whole story is that we've been relatively free of any major debilitating and chronic disorders throughout our lives. We have been exercise-conscious both in terms of participating in aerobic training and long distance running leading to marathons. Our lifestyle, over the years, has been free of smoking and consuming alcohol, and there has been a healthy observance of good dieting based on the four food groups. Admittedly, we've gone through a couple of stressful periods in our lives related to dealing with interpersonal relationships outside the home. Each time, we were able to work through the problem and come out stronger and better in terms of handling tension and developing character.

Our twenty-three years of marriage have been filled with periods of relaxation at home and abroad. In terms of the big picture of who we are in relation to our basic health needs, we could be classified as very average with nothing more serious than a thyroid deficiency and an occasional brush with infections. Sure, we like our food as do most Canadians but that, in itself, is enough to remind us to keep our waistlines under control with daily exercising. Our sense of keeping things in balance between what we need nutritionally and what we want intrinsically means that we're hardly ever given to excess.

4. Our Environment

The third factor in this triad of possible culprits is the environment or physical space in which we live and work. For a number of years, we have been aware that there is a significant selenium deficiency in the soil of the community where we live. Our area has some of the lowest levels in the country. Since this trace metal possesses some key cancer fighting qualities, there has been a continuous promotion in health food stores to purchase it as a mineral supplement. In this very pristine locale, there has been the ongoing environmental hazard of smoke emission build-up on days when there is a temperature inversion. This makes the valley one of the areas of highest particulate count in North America according to Environment Canada. Add to this the fact that Belle had worked for thirteen years in a smoky workplace before coming to this country in the late 1970's.

Though there is no hard evidence that we can find to prove a direct link to cancer, steady exposure to these environmental hazards might have a deleterious effect on our immune systems. People in our area are forever talking about the increase of certain kinds of cancer here over the past few years.

In short, while we're not living on top of a toxic waste site or knowingly ingesting toxins, there is a good chance of a gradual bodily accumulation of chemicals from the food we eat and the air we breath. These might very well collect in the fatty tissue and, over the long term, adversely affect the body's immune system. Studies show that much of our public drinking water contains low levels of toxins that are deemed safe within certain levels, but nothing is done

to ascertain effects from long-term accumulation. Belle has always been a great consumer of water to keep her body system flushed out. The amazing thing is that Belle has led an infinitely healthier life than I have when it comes to being immune to colds, flu, and infections, but she was the one struck down with cancer. Once again, however, her ability to ward off diseases might be the key to beating cervical cancer in the long run.

In terms of our living and actual workplaces, we both feel that we are constantly exposed to dust at home and poor quality air in our respective school plants. We know that we live in a very dirty environment, and steps must be taken to ensure that we don't succumb to any serious allergies. While we feel powerless to deal with the latter problem other than to complain, we have introduced an air purifier and special vacuum system to counter the former one. We console ourselves with the fact that Belle's regular intake of vitamin and mineral supplements, including kelp, has been sufficient to boost her immune system.

Neither of us smoke or drink, and of the two of us, Belle has the deepest breathing capacity. While we do like a wide variety of foods, we have always been very conscious of exercising in the form of daily workouts and runs to keep the weight down and muscles in good shape. I have run in a number of international marathons and done fairly well in them. The desire to exercise and keep fit has been passed on to both our children; one who experimented in being a vegetarian for a while as well as running, and the other who takes great pride in his upper-body strength. Both Belle and I have consistently good blood pressure readings and fairly stable pulse rates. Though we like our red meat for animal protein intake, we counter that with a lot of fruit, vegetables and fiber in our daily meals.

5. Another Factor - Apathy

Though Belle has struggled with a hyperthyroid condition (results in fatigue and weight gain if not treated) for the last twenty years, this has not hindered her from leading a fully involved life. From all appearances, we are a healthy family, with the occasional slip-up or illness that affects most families. Until this past year, cancer was not a subject readily talked about in our home. Why talk about something that only affects others?

In our home library, we have over 6,000 books - mainly history, economics, classic and modern literature. These extensive collections - while seemingly impressive - do not contain one medical dictionary or encyclopedia. That may very well have been because we never, as a family, expected to get seriously ill. When I contracted a serious staph infection in my left leg about four years ago, I trusted the local doctor to prescribe the right amount of antibiotics. I submitted to the treatment with only a mild academic desire to find out the cause of the problem. Our personal health was always secure in the knowledge that treatment was just a block away at the local hospital, and that we had our pick of what we thought were fairly competent doctors to make the correct diagnosis. Friends of ours might fall victim to cancer or a host of other serious ailments, but we always felt we had an aura of immunity about us. I can remember calling my friend Jim, the morbid 'Dr. Death', because he took such avidity in reading any literature on cancer and cardiac disorders.

Belle and I have always led very active lives: I ran marathons, golfed, hiked and climbed mountains while she was forever dieting, exercising and joining with me on extensive summer holidays as a way of getting away from the classroom. We led a very effective home life that

always seemed to have countless projects on the go: reading, writing, gardening, a home business, entertaining friends and strangers, special movie nights, reflecting, construction and cooking. Just a proverbial hive of activity where disease never had a hope of getting a foothold - or so we thought!

While there might be some interesting studies that prove a potential linkage between various forms of cancer and the environment, genetics and lifestyle, nothing in our profile could categorically affirm a more than casual connection. We only contemplated and studied these factors in the early weeks because we were eager to know the cause before we even knew the true nature of the disease.

Cancer essentially caught us by surprise. It quite often does with comfortably well off families who exemplify hard work, decency and sound family values. There is no one exact thing we could have done to prevent this disease in terms of our general makeup as human beings. In chapter 12, the reader will see that Belle's cervical cancer had little to do with environment, personal history or lifestyle but a lot to do with how she was handled by doctors at various levels. Having a hidden propensity for cancer - such as myself - does not alter the fact that it will always seem to sneak up on us without even so much as a warning. There is no absolute way - so much as a better way - to handle the surprise downturns in a person's life except to be more vigilant of our right to know vital information about our health. Quite often, we have to operate from a position of contracting the disease first before we begin to learn how to fight it. The following list represents things we did in those early days when we, the remaining family of three sensitive people, began to rally around the ailing member:

a. Quickly learn the full extent of the illness. This might entail a visit or two to a specialist and an array of tests. Prompt treatment then becomes the main priority.
b. Set up a plan that will guarantee the smooth running of the household during the absence of the parents. For us, it was comparatively easy because our two boys were virtually adults.
c. Involve other family members outside the immediate circle to help in the daily decision-making.
d. Discuss concerns with your partner as much as possible. Meaningful decisions can only be made collaboratively.
e. Discreetly pass word of the problem to others who might be able to help. There will always be those who are not ready emotionally to help and would rather not know.
f. Begin keeping a diary or journal of each day's situations. Such a practice has had enormous implications for us in terms of establishing a learning curve, recording vital evidence and allowing us to plan for the future because we see evidence of growth in the past.
g. Pick up a couple of self-help books or guides on your kind of cancer so that there is something to focus on when the mind begins to wander during the treatment sessions. The purchase of a fairly detailed medical dictionary is advisable if you don't want to continue stumbling over medical terminology. By all means, educate yourself on the possibilities for a cure and leave the second-guessing as to its origin for another day.
h. Don't revolutionize your outlook on life by 'cleaning house' and taking on the latest fad diet or quacky idea on how to fight cancer without the use of conventional medicine. As we warn in earlier chapters, radically recasting or reinventing your life as a means of casting out cancer is nothing short of being futile. Adjust to the new reality, by all means, but don't

think in terms of a radical 180-degree turnaround in character. It is not called for and may actually lead to more damage and disillusionment down the road.

i. Surf the net for some easy-to-follow web sites that will assist in making those important medical decisions. If we had to do this over again, we would have used the Internet much sooner. Check into the use of the e-mail and Internet as an inexpensive way of keeping in touch with the home, the community and research facilities. Don't overload your plate too much in terms of wanting to get things done at all costs. Learn to prioritize.

j. Be prepared to make some adjustments in priorities in your marriage; selfish attitudes are definitely taboo if you want to help your loved one make it through the tough times.

Footnote:

1. Easton, D. Familial Risks of Cancer. European Journal of Cancer. Vol. 35, No. 7. Pages 1043 - 1045.

Chapter 12

How Reliable is the Pap smear?

How would you feel if the only thing standing between you and death was a simple medical procedure? If taken annually or biannually, it will assist greatly in helping to detect the presence of early abnormal cell growth in the cervix. Immediate treatment will prevent the spread of cervical cancer if caught soon enough.[1] Would you feel reassured that this method of cancer detection called the Pap smear test (named after George Papanicolaou in the middle 1930's) is endorsed by dozens of prestigious medical organizations around the world? These include Health Canada and the Centre for Disease Control to name only two. The test is virtually error-free in delivering reliable diagnoses.[2]

The answer would likely be a resounding yes at this point because there would be no reason to distrust the physicians who administer the test, the pathologists and technicians who analyze it or the oncologist who diagnosed it. There are claims that if a Pap smear doesn't detect dysplasia, (irregular cell growth) it is not the test that has failed but one of those rare situations where technicians just couldn't possibly read the sample because of the uniqueness or obscurity of the cells.

As reasonable people who are prepared to accept a margin of error in any kind of testing that involves human observation, we would reluctantly accept the fact that some Pap smears can be misread once in a while. According to the Miami Herald of July 9, l996, the Pap smear test has been found to be increasingly unreliable in both evaluating and sampling. Up to as many as 30% of the tests in some American cities are turning up as misreads with a smaller percentage of these resulting in full-blown cervical cancer.[4]

Any number of things can, unfortunately, go wrong with the procuring of Pap smears. These can include obtaining an inadequate sample from the wrong part of the cervix, having the sample dry out thus distorting the cells, or having the sample obscured by inflammation or blood.[5] In the latter case, most screening labs and agencies would regard it as sub-optimal and request a retest or further investigation. It is an absolute no-no, in the first place, to even take a smear during a menstrual period. However, a certain respected local doctor told us that she often took a sample during a menstrual period after she had attempted to clean up the area. Other equally respected sources tell us that such a practice only bruises the surface cells and doesn't make the smear any more effective.

In Belle's case, the local doctor went ahead and took a smear without even attempting to clean up the cervical area or checking out the cause of the irregular flow. We've been told on good authority that re-testing is quite often not any more accurate than the first try because the problem of a heavy flow may still be there. Rereading the slide is just as futile because a new part of the slide is analyzed each time and no attempts are made to compare with other areas of the sample. In other words, a bad quality slide yields little of value that can help in the detection of cervical cancer. Taking a poor sample and having it analyzed as negative (no irregular cells) is compounding and concealing a problem that has the potential to be invasive cancer of the worst kind. Standard of Care in Texas suggests that the Pap smear is pretty well useless in detecting invasive cancer because it has no way of picking up cancerous lesions due to excessive

blood and inflammatory exudate. This legal group also says that Pap smears have only a reduced amount of success in terms of more advanced stages of cervical cancer.

According to our research, all these problems involving the quality of the smear are of a technical nature and can be remedied on the spot with such techniques as spraying, purging, re-testing or other exploratory means such as the colposcopy.[6] These were options that were not suggested to Belle when her original test was returned to her as negative in June, l998.

It is our belief that, while the Pap smear has helped to significantly reduce fatalities in cervical cancer through early detection, we should not be lulled into thinking that its results are inviolate. This is because of a higher than normal potential for error in certain age groups such as older women. Some estimates are as high as 30% to 50% false negatives.[7] This term refers to a Pap smear that should be called positive but is mistakenly classified as negative and quite often leads to cervical cancer because of a failure to take due note of the changing symptoms.

Most screening agencies in North America have a criteria that allows the technicians the right to make marginal calls that distinguishes between benign atypia and mild dyskariosis[8] based on the number of irregular cells viewed. The former can often be mistaken for the latter and go unchecked for a couple of years. Since a lot of the in-lab analysis in Canada is done manually, without the aid of an electronic scanner, this might lead to a certain number being misread because of a poor sampling technique, poor sample quality or poor sampling evaluation. Though there are standards that allow a screening lab to recommend to a patient, through her local doctor, the need to further investigate suspicious results, this does not alleviate the fact that things can be missed either at the beginning or end of the process. All it takes is for the patient never to be informed of all the information on her Pap smear transcript for the process to break down.

There should be a rule in place that screening should err on the side of caution and the patient's best interests. Far too often, human error is naturally factored in as being spread out over hundreds of thousands of smears annually, so deemed to be of little consequence. The problem is likely greater than what a screening agency might refer to as the low incidence of mild dysplasia progressing to SIL (severe intraepithelial lesion). If our provincial agency is anything to go by, all smears are reviewed manually in-house with the full knowledge of the patient's history. Not much reliability here when the reputation of the lab is at stake. The bias is definitely in favor of the lab when it comes to rereading slides. Receiving these results over the telephone from the local physician is not good enough either especially when it is a receptionist/nurse who relays the information on his behalf.

It is Belle's unfortunate experience to have never had the opportunity to discuss with any doctor the changing implications of a smear result for a woman going through perimenopause into menopause. The test was simply administered, the sample labeled, shipped off and the results returned later to be relayed to the patient by a phone call. The abnormal bleeding recorded on the transcript was not checked into nor was there any attempt to get a full history of Belle's menstrual cycle. If mild to moderate dyskariosis had been detected at that time, as it was upon further review, a pathologist would have ordered further investigation.[9]

In this modern era, when so many doctors are taking short- to long-term leave, it is not unusual that as many as three doctors get to see a patient's file with very little chance of vital information being acted on. Some doctors might believe that heavy bleeding is only symptomatic of important body changes due to a change in the estrogen level so will tend to dismiss it as a passing problem to be monitored periodically. Our advice to all women is to

challenge the dismissive attitude of any doctor who sees the rather serious symptoms as possibly something trivial. Consider this your right because your life may be at stake!

A. What is a Pap smear?

The Pap smear is a test that is universally used to detect the presence of abnormal cells and lesions growing on the surface or epithelial cells of the cervix or endocervix. It is a relatively painless, non-invasive procedure. A doctor inserts a spatula (a long tipped one is highly recommended) into the vaginal canal after it has been opened by a speculum (a device used for opening orifices such as the vagina) for the purpose of scrapping tissue from the surface of the cervix.[10] During a recent visit to her gynecologist, Belle had a Pap smear done in less than 30 seconds. The sample was then taken, labeled, packaged and sent to a provincial lab for analysis under a high-powered electron microscope. At the lab, the sample would be mounted on a slide, stained to accentuate cell life and evaluated for evidence of enlarged or distorted cells.

There are many hundreds - yea, thousands - scrutinized each day with an average of less than five minutes for what must be a very tedious examination of each slide.[11] It is an assembly line process in which a judgment call has to be made as to the classification of evidence. A gynecologist once told us that a lot of the analysis comes down to determining on the spot one classification as opposed to another. According to her, there was not a lot of consensus some of the time. It is no secret that this must be an extremely stressful job for any technician especially if there are no provisions for immediate control re-testing such as outlined in the Bethesda System.[12] Every measure is taken to ensure the confidentiality of each technician in their efforts to render reads and rereads of slides.

B. What evidence should the Pap smear test yield?

There are a variety of suspicious results that can show up on a Pap smear. They are everything from normal cell growth, to tissue obscured by blood or inflammation, to the presence of viral changes such as benign atypia, to mild/severe dyskariosis, to severe dysplasia to cervical carcinoma.[13] There is a distinct option for each of these findings: a regular Pap smear in one or two years if it is normal, re-testing at a later date if mild abnormalities appear, exploratory investigation if serious abnormal cells exist or treatment if cancerous cells are detected.

Our concern is that a technician generally grades the Pap smears and makes a recommendation quite often on what he can't see as opposed to what he can. For example, it would appear that cytotechnicians have the power to sometimes call a sample negative when it is difficult to read because of blood and mucus. All they have to see are a few cells that look healthy in order to pass it as negative. This is often referred to as a potential error in diagnosis because it neglects to take into consideration certain suspicious signs such as the presence of inflammation or the absence of endocervical cells.

Our provincial screening agency's protocol for Pap smears is still one based on general categories that demand a large presence of abnormal cells in order to be red-flagged. The Bethesda classification system, introduced in l988 in the USA, classifies cellular growth in terms of allowing atypia (abnormal) cells to be graded as high- or low-grade quality. This permits a greater degree of latitude in recommending further investigation. Benign atypia, which ideally

indicates that the cells will return to their healthy state, should not be lumped in with mild or moderate dysplasia which has a greater chance of progressing to invasive cancer. We have yet to discover the criteria for differentiating between benign and mild atypia cells, other than the fact that it is a judgment call. Some technicians see it one way while a cytopathologist might see it the exact opposite. High-grade situations (based on size and number of colonies) obviously warrant immediate review before sending a result back to the local doctor.

In Belle's case, upon a recent request for a review of her last three Pap smears, two mild dyskariotic readings, in an ideal situation, should have resulted in the agency recommending re-testing after six months or a pelvic examination by the local doctor. At a certain age - approaching fifty - all women should receive an annual Pap smear to circumvent the problem of having to wait another two years before having another one. Remember, cervical and uterine cancer are diseases that do not show clear, unmistakable symptoms like weight loss, itching of the skin, dehydration and vomiting until the cancer is well advanced. A parent of a colleague of mine, unfortunately, became aware of her cervical cancer by feeling a lump in her chest. By then, it was too late, and she died two years later.

C. Major problems with the Pap Smear.

Our research on the subject reveals a host of concerns about the Pap smear, none of which attack the integrity of the test if it is properly done. Not surprisingly, most of these disclosures and changes come from south of the border which probably indicates a greater willingness on the part of health officials to address these concerns rather than ignore them. In the first case, the spatula for taking the sample may not penetrate far enough into the cervical rim or tunnel to catch the transformation zone (area between the cervix and the vaginal wall).[14] Secondly, the lab may receive a sample that has not been properly cleansed of blood and exudate and, once again, dismiss it out of hand as a false negative.[15] In another scenario, a careless or hurried reading of a sample may overlook the existence of some specific abnormalities in relation to gross or general normality and, consequently, render a false-negative reading. Don't forget that cervical cancer is a slow growing disease, and every little clue is needed to detect its insidious presence.

D. What improvements are presently being made to the Pap smear testing protocol?

We reiterate, for the express purpose of this book, that the Pap smear test is a sound, non-invasive technique which, when taken under the strictest of terms, saves lives. Admittedly, it might be difficult, even for the trained eye, to detect small clusters of irregular shaped cells amongst a tissue sample of 300,000 or so. But, again, it is not the Pap smear that is at fault but the rather arbitrary 'hit and miss' technique used for handling it. The literature on the Pap smear protocol that is available to every patient entering our provincial agency suggests that anyone slipping through its screening system is an unavoidable case of accidental misdiagnosis. We have been told that a good number of private and public laboratories in both Canada and the United States now use the Bethesda classification method for rating types of smears on the quality of cell growth. Any sample that shows suspicious cell growth or obscured results is immediately subject to re-testing with procedures such as the NMP 179 test (measures protein in the cell) that is 92% sensitive to predicting cervical dysplasia.[16] Unfortunately, Belle's Pap

smear was evaluated under a less stringent system that doesn't recommend a review unless there are consecutive borderline slides.

A number of cancer agencies and labs across the country have adopted a backup computer system that allows microscopic analysis of all samples that show little or no cell irregularities. Our provincial lab is in the process of overhauling both its classification model and its assessment protocol. From a cost perspective, if a test like this were available, it could cut back on a very expensive cytological review and colposcopic assessment. Recently, a report came out from a British hospital recommending that doctors use a long-nosed spatula rather than the conventional short-nosed one in obtaining a more reliable tissue scraping from the upper regions of the cervix. This tool is more expensive than the traditional Ayers model and might not catch on with local doctors who are working on tight budgets.

The above developments are critical in light of the 10% to 20% of 4,000 to 5,000 new cervical cases being reported annually as false-negatives in the United States.[17] It should be mandatory that all negative results involving suspicious conditions like inflammation or heavy bleeding should be subjected to a second look. In Belle's case, her doctor ignored the information that was attached to her transcript. If any findings warrant closer examination, the local doctor, on his own volition, should conduct a colposcopy without delay so that a tissue biopsy can be examined for cancer. It should be noted here that there is nothing compelling the local doctor to conduct any subsequent testing except his own professional integrity.

Once again, the Pap smear would have done its job as an early warning but should not be relied on beyond alerting the doctor and patient to a problem. In fact, a copy of the results, with a detailed explanation of all concerns, should be mailed directly to the patient highlighting any potential problems. The time has come to involve the individual patient directly in the process of taking personal care of one's health. In Belle's case, all communications were strictly between the agency and the doctor, and she never learned of any abnormalities on her record until after her first treatment. We believe that this is the fate of many women, in society today, who have entrusted themselves to the care of professionals who virtually treat them like a number.

There is another problem concerning the inaccuracy of the reporting of Pap smears. According to Hildensheim et al., it is one of the contributing factors to rapid onset cervical cancer as manifested by adenocarcinomas or glandular tumors in the endocervical region.[18] It is that area that often gets missed in the initial screening. With Belle's samples, we have also encountered some very questionable screening practices that border on the sloppy. This makes it near impossible to discern what is an accurate reading between the cytopathologist and the technician. It would seem that we have had to challenge the validity of each review done on the original set of smears because they contradict each other. As of the middle of 1999, the agency would appear to have issued yet another review that attempts to remove all the glaring inconsistencies and disparities - with the two disparate screening groups reaching a safe consensus. All the questionable Pap smear reviews have been virtually erased.

One of the rules of thumb in analyzing Pap smears, according to Sue Schlafmann, a pathologist, is that careful monitoring is required to make sure mild dysplasia does not progress to become cancer.[19] If such suspicious evidence is not originally checked out, there might be some serious concerns later on as to when the cancer began. In a legal situation, this oversight often results in confusing the evidence of the original smear and its subsequent revaluation showing a false negative. Our advice to all women is to look at their Pap smear results more closely, discuss with their doctors the risk factors associated with their age group and insist on an

annual physical that includes a pelvic examination especially if there are any suspicious signs such as bleeding, fatigue, etc.

E. The future of cervical cancer in North America versus the developing world.

There is a tendency for statistics to lull people into thinking that cervical cancer, relative to other diseases in the world, is well under control in Canada and the U.S.A. Only 9% of all cancers reported in this country are of the cervical/uterine nature so why worry when leukemia, breast and ovarian cancers are much higher. Hasn't the Pap smear test done its job - in the last seventy years - and all that women have to do now is get into the routine of having an annual Pap smear and physical?

Where we come from, such implicit faith is bordering on the absurd and complacent and, to say the least, quite unearned as far as the Pap smear is concerned. We are a very sexually active society, and statistics show that there are large pockets of our population that have not yet been reached with the Pap smear. In the rest of the world, cervical carcinoma is one of the most prevalent of cancers and biggest killers (450,000 new cases annually).[20] Admittedly, much of the problem is due, in large part, to neglect of personal health, ignorance of early signs and enforcement of traditional customs. To break down these barriers of distrust and nescience, the WHO (World Health Organization) and many national groups are waging a public campaign to educate women in the use of the Pap smear.

Sounds good, but consider how widespread AIDS (Acquired Immune Deficiency Syndrome) is in Africa today as a result of a very sexually active society. Then see it in the light of trying to control cervical cancer throughout the developing world and you've got yourself one enormous problem to eradicate. We, in Canada, should be well beyond the stage of introducing the Pap smear to women for the first time. Women should see the results and have them explained in order to better understand and make informed decisions. Forewarned means to be forearmed. No physical checkup should take place without a detailed Pap smear transcript being available in conjunction with a pelvic examination. Every patient who undergoes a Pap smear on a regular basis should be alerted to the possibilities of cervical cancer especially during certain times in life.

F. The Prospects of a cancer vaccine for cervical carcinoma.

We've been told, on good authority, that any work on establishing a cancer vaccine is really still in the formative stage. As this research proceeds, its main thrust is to attack the antigens (check glossary) E6 and E7 (protein) in the P53 gene (controls cell growth and replication) with a substance that activates the antibodies and T-cells to create apoptosis (cell death). The Papilloma virus (HPV), in attacking a surface cell on the cervix, is incorporated into the P53 gene and forms an oncogene (E6 and E7) which produces an excessive amount of protein that promotes wild and irregular cell growth.[21] The key to this might be the injection of protein kinase inhibitors (check glossary) in the form of peptides into the wild cells to encourage the immune system to do its job. At present, a lot of apoptosis (tumor destruction) is done through

chemotherapy and radiation in which the antigens (proteins) in the defective gene are severely knocked back to the point of not being able to recover.

According to the reports we've read on the subject, very little is known as to why T-cells (main line of defense against infection) remain passive in some cases of the E6 and E7 and not in others. Until a safe vaccine has been found, the traditional methods mentioned above, with the addition of cistplatin-fluroacil, are being used without having to detect the presence of the wild P53 gene. Some variants of the HPV (16 and 18) can be sensitized or disturbed to respond to cervical cancer in different areas and stages. The problem with using radiation treatment with the P53 gene is that oncologists don't know for sure what the lethal dosage is to bring the tumor under control. P53 and Rb (gene type) are considered major tumor suppressor genes and shouldn't be destroyed completely if it is a matter of restoring normal cell growth and reversing the process. Our immediate reservation about vaccines is not to pin too much hope on their future inception. While a breakthrough might come in terms of a miracle vaccine or drug, the real research is currently going on to improve present detection and treatment modalities including the Pap smear. Early detection and effective vigilant screening become the rallying cry for all women who might be susceptible to false negatives or misreads.

Since we've formed an interest in the Pap smear, new and improved technology has become available to women, which puts a bigger emphasis on identifying the presence of the HPV as opposed to looking for abnormal cell growth. Presently, it is proving difficult to establish a test that confirms the presence of the many strains of HPV accurately. The Digene Corporation in the USA has developed a genetic test that allows detection of certain viruses in the human cell. This kind of test, if it lives up to its billing, will act as an adjunct to the Pap smear test and catch a lot of the borderline cases of ASCUS that might normally get passed over. Another test called the NMP 179 (nuclear matrix protein) is used after the Pap smear to determine the levels of protein buildup in the cervical cells.[22] From this, it can determine if the patient in question is at risk for contracting cancer. Such a procedure is expensive especially since it is still in the early stage and only released to large private hospitals in the United States. Its cost could be justified if it could be shown to further eliminate a lot of that 20% to 30% group that shows slightly abnormal cell growth. All slightly irregular cell growths should be checked every six months to determine the regression or progression of the lesion.

Nothing should be left to chance; doctors and technicians should err on the side of caution when the smear appears to be suspicious in nature so that there are fewer Belle's in this world that have to be written about. From her perspective, the only thing that saved her life was the fact that the malignancy decided to first metastasize in her right groin as a lump rather than move to her vital organs.

Footnotes:

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3. Cervix-Cancer Information Base. www.bccancer.bc.ca
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7. Pap Test. www.erinet.com/fnadoc/ and www.bccancer.bc.ca/cid/12.html
8. www.nmmc.com/nmhc/library/htm/papsmear.htm
9. The Gynecological Tumor Group Screening Protocol. www.bccancer.bc.ca
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12. www.hncbc.nlm.hih.gov/apdb/CERVCAN9/REPORT.HTM
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14. Common Pap Smear Tool Ineffective. www.drkooop.com/news/focus/november/cancer risk.html
15. Tips for Making Good Pap Smears. www.neosoft.com/~uthman/pap_tips.html
16. New Test May Reduce Uncertainty of…Abnormal Pap Smears. Primary Care and Cancer. April, 1999.
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20. www.health.fgov.be/WH13/krantarch99/kranttek
21. Kilic, G. et al. Human Papillomavirus 18 Oncoproteins E6 and E7 Enhance Irradiation. European Journal of Gynecology and Oncology. March, 1999. Pages 167-171.
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EPILOGUE

It has been almost ten years since Belle first learned that she had cancer and began an extended journey to recovery. A number of important things have transpired over that time; the most important being that Belle has recovered sufficiently to get on her with her life and enjoy a modicum of good health. Of course, there are certain side effects that still linger like the restless-leg syndrome that might keep her up part of the night, neuropathy in her feet and the sense of fatigue that usually catches up with her by mid-afternoon on most days. And, in case I forget, there have been a couple of scares along the way related to suspicious bleeding. She has been fortunate in being able to qualify for long-term disability benefits from her employment, so she hasn't worked out of the home since mid 2000. This has given her lots of time to rest and relax while applying herself to some jobs around the house.

Both our children have grown up and left the home long ago: Peter is now married and working for Norad in Colorado, while Eliot has graduated from Simon Fraser University and is working in Vancouver in film making, graphic design and a restaurant/theatre.

Our legal efforts fizzled out several years ago due, in large part, to the difficulty of finding expert testimony to back up our original contentions.

As Belle's husband, I still teach high school history, though I have passed the retiring age. I spend a lot of my free time working on my web site (malcomsonline.com) and have published stories of my life in the classroom online for anyone to read. Between the two of us, we pack away at least six books a week in a wide variety of subjects.

We have been blessed with numerous opportunities to travel to Arizona and Oregon, and abroad to Paris, Ireland, London and Wales since 1999, and will continue to seek out great spots for holidaying, like Colorado, hopefully, this summer. We have switched spiritual families since then and presently worship at the Evangelical Free Church where we feel very at home. Over all, we can say with absolute certainty that God has been very merciful to us both in allowing us to enjoy all these extra years together in relative peace and confidence.

GLOSSARY OF TERMS

1. Adjuvant Treatment: This refers to additional support treatment over and beyond the basic protocol. This can be done to either reinforce the main course or offer the patient another kind of treatment. Belle had adjuvant therapy with the carbogen intake to improve her cell exposure to the radiation and chemotherapy.
2. Allele: A combination of one dominant and one recessive gene in the chromosome. Where the normal dominance is lost or blurred, a mutation or cancer is likely to occur. A good example of where the dominance is clear is in the characteristic of the P-53 gene that is inherited from one of the parents and may allow a person to resist the HPV effectively.
3. Anemia: A condition of low hemoglobin (iron) in the blood that causes fatigue. In the case of cervical cancer, it is generally the result of a continual heavy bleeding due to the onset of the invasive stage.
4. Antigen: Any protein substance coming from a virus that causes antibodies or resistance to the presence of toxic material in the cell.
5. ASCUS: This stands for atypical squamous cells of undetermined significance. This condition generally implies that the technician may or may not have seen anything of real significance when viewing the sample.
6. Atypia Cells: Classified as slightly irregular, pre-cancerous cells with enlarged shaped nucleus. Cytotechnologists (people who examine the smears in the lab) generally look for clusters or groups as an indication of the extent of an abnormality.
7. Ayers Spatula: A long tipped spatula used for reaching into the cervical canal to get at the endocervical region.
8. Bethesda System: This is used by a lot of screening clinics to classify abnormal cell growths in terms of different levels of atypical cells. This is a more advanced system because it recommends investigation of atypia or abnormal cell growth earlier in the process.
9. CAT Scan - computed tomography: It refers to a non-invasive series of circular x-ray images taken while the subject lies on a table and a camera rotates around the full length of the body to get a composite picture. In Belle's case, it was useful for determining, in the initial stage, if the cervical cancer had broken out from the pelvic region. It is not very helpful after treatment because the resolution is not powerful enough to pick up any small remnants of cancer residing in a person's body.
10. Carcinoma: A tumor that originates in the lining of organs such as the genitals, lungs, liver or stomach and is often regarded as another word for a malignant tumor.
11. Cell Fractation: The distribution of radiation to key areas over a certain duration of time.
12. Chemotherapy: The process through which systemic cancer is treated by the ingestion of a cocktail of toxic chemicals, such as cisplatin, that have the proven ability to mutate and destroy the nucleus of cancer cells. They come in various classes with the alkalynic ones being used for the more serious cancers such as cervical and ovarian.
13. Cisplatin: A derivative or form of platinum which is capable of destroying toxins in cells - check out this web site on cisplatin (From Basic Research to Cancer Drug: The Story of Cisplatin) www.the-scientist.library.u…/yr1999/july/lewis_p11_990705.html

14. Clinical Trials: Scientifically organized experiments with new drugs to be used in combating cancer. To qualify for these extended studies, a patient is advised to check the web site for National Cancer Inventory.
15. Colposcopy: The examination of the cervix by removing a small slice of tissue from the cone region for examination. A speculum is used to open the vagina to give good access to the cervical region.
16. DNA: (deoxyribonucleic acid) The essential chemical from which the genetic code is formed in each cell. It is found as a helix spiral inside the nucleus.
17. Dyskariosis: The pre-malignant state of cancer cells.
18. Epithelial tissue: Refers to the surface tissue that lines the walls of organs such as the cervix. It is where cervical cancer gets established before moving into the squamous cells. They are shaped like columnar scales. It is usually interpithelial squamous cells (taken from the transition zone - the area between the cervix and the endocervix) that signal the presence of cancer in a Pap smear.
19. False-Negative: Occurs when a Pap smear test is misread in terms of stating a negative (no suspicious cells) when it really is a positive (very malignant cells). Any other misinterpretation of a Pap smear is regarded as a misreading which is serious but hardly in the same ballpark as a false negative.
20. Hemoglobin: Refers to the iron content in the blood.
21. Heterozygosity: Each chromosome in the gene comes in pairs - one dominant, the other recessive. When mutation is in the gene, that significant difference or strength is lost in terms of that characteristic such as controlled cell reproduction.
22. High-Beam Selectron: This is the name given to a high powered, photon particle beam radiation machine used to radiate cancer. It is called this because the beam is from outside the body, can be moved and trained on selected spots.
23. Human Papilloma Virus (HPV): Very small disease-producing agents that come in a variety of strains and are known to cause different herpes infections, not the least, cervical cancer. By definition, they are the agents (papillae) that cause protrusions to form on mucus surfaces.
24. In Situ: The cancer is contained to the surface cells around the cervix or endocervical area in the form of neoplasia (beginning abnormalities) and dysplasia (established abnormal cells) which would show up on a slide as small colonies of suspicious atypical squamous cells or intraepithelial squamous cells. This is the stage at which decisive action is taken to remove the malignancy through cryotherapy (freezing the area in question so that the abnormal cells become detached and are replaced by normal ones).
25. Inguinual Node: One of a number of lymph centers found in the pelvic region. Apparently, there are thousands of them throughout the body that serve as a defense against the spread of infection.
26. Internal Beam Radiation: In this process, two hollow rods are placed inside the vaginal tract and then linked to a machine by tubes. Radioactive seed pellets are shot through these tubes and rods to the primary source of the carcinoma. This helps to concentrate the radiation over a 12 to 16 hour period. The seeds do not leave the rods but are actually withdrawn or recollected every time the process is stopped.
27. Invasive cancer: This is the stage in which a tumor breaks off and spreads to other organs.
28. Lesion: Refers to disease changes in organ tissue. This can be either a pre-malignant or malignant state.

29. MRI - Magnetic Resonance Imaging: X-ray technology that is more advanced than the CAT Scan and used mainly for the brain. It uses a magnetic dye to react with the radioactive beam.
30. Metastases: The spread of cancer cells through the blood stream or lymph system to set up new colonies or groups.
31. Mmenotaraghia: Heavy and irregular menstrual bleeding. Every doctor encountering this should request a detailed history of the menstrual pattern from the patient.
32. Mutation: Irregular growth and development of the cells due to an inordinate amount of protein being produced.
33. Nausea: The feeling of wanting to vomit. This is usually caused by the toxins attacking both the cancerous and healthy cells or radiation building up in the body. Anti-nausea drugs are usually recommended to mitigate some of the more serious side effects. It can sometimes take up to a month or so after treatment to rid the body of nausea.
34. Needle Biopsy: This is the procedure by which a long needle is inserted into the area in question and tissue is withdrawn in vacuum-like fashion. This method is considered less invasive than surgery and used in drawing biopsies from areas such as the lungs.
35. Negligence: Failure to do what is professionally expected in terms of specific medical procedures, i.e. excessive bleeding requires further investigation.
36. Neoplasia: The beginning of abnormal cell growth - usually indicated by small colonies of suspicious cells on the smear sample.
37. Oncology: The study and treatment of tumors through radiation.
38. P-53 Gene: The main gene responsible for cell reproduction.
39. Palliative Care: Extended care given for the purpose of easing pain and discomfort for someone who is designated terminal. This might involve receiving radiotherapy to ease pain coming from cancer in the spinal column.
40. Panhysterectomy: An extensive removal of the female genitalia involving ovaries, uterus, and cervix. This is a standard operation for lessening the chances of cancer recurring in this area.
41. Pap Smear: A test to determine if abnormal HPV type cells are growing in the cervical and endocervical region. This is usually done by inserting a spatula and taking a scraping of surface cells at or in the entrance of the cervix. This scraping is mounted on a slide, stained and examined for abnormal cell growth. This method is excellent for early diagnosis and determining if further investigation is required. It doesn't, in itself, locate cancer except in the very advanced stages.
42. Para-aortic Region: The lymph region that is found between the pelvis and the chest (thoracic) region. Belle received radiation in this area, the second time around, to irradiate chances of cancer spreading there.
43. Pathology: The study of the causes of diseases. In Belle's case, there was extensive lab analysis done on her ovaries, uterus and cervix after the hysterectomy to find out if the treatment had been successful in eradicating the cancer.
44. Platelets: The cells in a person's blood that cause clotting - this is one of a number of components that doctors observe closely to see if a patient is responding well to treatment.
45. Polymorphism: A band of different hereditary characteristics found in a gene.

46. Protein: A complex nitrogen-based compound that plays the role of building up and helping to reproduce cells. Too much protein can lead to irregular cell development and eventually cancer.
47. Remission Versus Relapse: The standard for remission for most cancer agencies is when there is no sign that the cancer is spreading and that tumors are actually shrinking. Relapse, on the other hand, is when the cancer breaks out again in the same or another area. As remission proceeds, the checkups are spaced further apart. Some agencies might consider the five-year mark as a safe point for considering remission to be underway. Belle's doctors did not talk in these terms because cancer can come back anytime - it's just a little less likely with each advancing year of remission.
48. Stage 4B: This is the most advanced, extreme stage of cancer progression where the carcinoma has broken through the pelvic wall and moved out into other organs. Long term prognosis is not very good at this stage. Belle was given a Stage 4B only because it was Stage 3B with traces found in one of the lymph nodes.
49. Staging: Examining the pelvic area to determine at what stage the cancer is at. There are generally four main stages that indicate that the cancer has moved from a local to a more invasive state.
50. Systemic Cancer: Refers to a certain part or system of the body. Belle had systemic cancer in her genitalia in the sense that it was well spread throughout that region.
51. Uterus, Vagina, Ovaries: Major reproductive organs found in the pelvic cavity of a woman and considered part of her genitalia.
52. White Cell Count: Refers to the corpuscles (to fight infection) in the blood stream. If they are high, it is generally an indication of an infection or a body reaction.
53. Wild gene: A healthy gene that is resistant to cancer - in other words, it has not been damaged by any mutation. As part of one of the 46 chromosomes in the cell, a healthy gene controls a particular aspect of the human body's development.

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Cass, Ilana et al. Molecular Advances in Gynecological Oncology. Opinion in Oncology. November 1999.
This is a most helpful article in clarifying how the molecular structure of gynecological cancer can be linked to the formation of oncogenes (defective or mutated genes within the DNA) and the excessive presence of protein. Once again, having a medical dictionary is a must for effectively mining this article for clues as to the possible origin of cervical cancer.

Current Medical Diagnosis & Treatment, l999. A Lange Medical Book, Appleton & Lange, Stamford, Connecticut. Chapter 17.
This is probably one of the better general sources for covering the essential details of cervical carcinoma, its stages, and treatment.

The DNA Testing May Facilitate Identification of Women at High Risk for Cervical Cancer. Primary Care and Cancer. April l999.
This article looks at a new kind of test that is meant to supplement the Pap smear in terms of identifying high-risk cervical carcinoma types. This would be done by analyzing the DNA in terms of detecting the presence of E6 and E7 protein codons or even picking up on the presence of any number of HPV strains. The NMP 179 model (nuclear matrix protein technology) correlates the amount of NMP in the body with the presence of cancer to determine the risk factor.

Garipagaoglu, M. et al. Prognostic factors in stage 1B - 2A cervical carcinomas treated with postoperative radiotherapy. European Journal of Gynecology and Oncology. February l999.
This study looks at prognostic factors such as the size of the tumor, depth of invasion and staging to determine whether a patient will succeed with adjuvant radiation after surgery. The findings were that where the tumor was less than 40 mm. and radiation was part of the routine treatment, there was usually a significant rate of five-year survival. This study is from the Middle East and was completed well in advance of the advent of cisplatin combined with radiation treatment.

Giannoudis, Athina et al. P53 Codon 72 Arg/Pro Polymorphism is not related to HPV type of lesion grade in low- and high-grade squamous intraepithelian lesions and invasive squamous carcinoma of the cervix. Int. Journal of Cancer. 1999.
This is a very technical article that attempts to look at connections between a polymorphism (an alteration of the genetic form) in the P53 gene and the presence of the E-6 protein coming from the HPV (human papilloma virus) which quite often leads to cervical cancer. This is a useful article if one is prepared to read it over again, study it carefully and learn some new vocabulary.

Grigsby, Perry et al. Lack of Effect of Tumor Size on the Prognosis of Carcinoma of the Uterine Cervix Stage 1B and 2A Treated with Preoperative Irradiation and Surgery. International Journal of Radiation Oncology, Biology, Physics. Vol. 45, No. 3, Pages 645 – 651.
This clinical investigation concludes that staging (treatment for 1A-4B) is all-important for determining success of surgery and radiation in treating cervical cancer. This emphasizes one of the main points in this book that early intervention is critical for overcoming this problem.

Gynecological Cytological Screening Program in BC.
This guideline sets out a number of important requirements and criteria for proceeding with Pap smear screening. Everything is covered in terms of the actual technique for obtaining a smear, interpreting it, validating its quality and recommending treatment. This is also available at www.bccancer.bc.ca. There is one drawback to this system in that it does not have specific categories for atypia cells such as found in the Bethesda System. Consequently, there is the broad category of dyskariosis that covers anything from mild to severe with no firm recommendations for either re-testing or further investigation at the lower end of the scale. It is this protocol that we are using in our present probe of the agency. This protocol can be obtained by logging on to www. bccancer.bc.ca/cmm/gynecology/01.shtml.

Hellebrekers, B.W. Zwinderman et al. Surgically-treated early cervical cancer: Prognostic factors and the significance of depth of tumor invasion. International Journal of Gynecological Cancer, l999. Pages 212-219.
This article was included in this bibliography to make the point that early intervention is essential for effectively and correctly dealing with cervical cancer. This is a very well researched study in regards to the size of the sampling population and research criteria.

Hildesheim, Allan et al. Risk Factors for Rapid-Onset Cervical Cancer. American Journal of Obstetrics and Gynecology. March 1999.
This study is valuable in impressing on the reader that cervical cancer has different staging characteristics for different groups in society. Rapid-onset cervical cancer is usually associated with younger white women who use a form of oral contraception. It was also found to be present in women who had a glandular form (adenocarcinoma) rather than a squamous form, which quite often results in false-negative smears because it is well within the cervical canal. The strong message that comes through is that women should have a Pap smear on an annual basis and have the results thoroughly discussed in relation to a physical and pelvic examination.

Holowaty, Philippa et al. Natural History of Dysplasia of the Uterine Cervix. Journal of the National Cancer Institute. February 3, l999.

This review is based on an actuarial life-table analysis of a large group of women, in the Toronto area during the l960's and 1970's, who were found to have a range of mild to moderate to severe dysplasia. The findings are interesting in that they show that the majority of mild dysplasia returned to normal, while the moderate had a 16% progression rate to severe within a two-year period. This is ideal information to have when looking at how many screening labs treat the differentiation of mild dysplasia from a benign or negative find. Some cytopathologists suggest that it is such a close call that it could go either way. I say, in response, that it is high time that they began erring in favor of the patient.

Human Papillomavirus Testing for Triage of Women. Journal of the National Cancer Institute. March, 2000. Vol. 92. No.5.

This bulletin emphasizes the point that Pap smear testing is ideally suited for dealing with the disease at an early stage. Other forms of investigation have to supplement it if it is truly to be effective as a screening tool.

Kilic, G. et al. Human papillomavirus 18 oncoproteins E6 and E7 enhance irradiation and chemotherapeutic agent-induced apoptosis in P53 and Rb mutated cervical cancer cell lines. Oncology. January, l999.

This study takes an interesting look at induced apoptosis (cell destruction) through the use of agents including cisplatin and adriamycin. The existence of the P3 gene in the chromosome serves mainly to suppress tumors but is also susceptible to the HPV when it's mutated. This raises a number of possibilities of treating cervical cancer types with drugs - such as protein inhibitors - that respond very well to various kinds of HPV mutation or wild forms (active). Once again, be patient with this study because it deals at quite a high conceptual level.

Liaw, Kai-Li et al. Detection of Human Papillomavirus DNA in Cytologically Normal Women and Subsequent Cervical Squamous Intraepithelial Lesions. Journal of the National Cancer Institute. June 1999.

This study followed over 23,000 women to see if the HPV was present in the development of squamous intraepithelial lesions. In the majority of cases, the HPV-16 variant was discovered in the DNA of cancerous cells exfoliated from the cervixes of over 700 women. This is a very rigorous longitudinal study that seems to meet all the rigors of case-controls and cross sectioning.

Loxterkamp, D. Facing Our Morality. Journal of American Medical Association. September 8 l999.

This article is a clarion call for doctors to return to listening more effectively and compassionately to their patients rather than imposing their will on situations that may not be truly understood. The real skill in handling patients, like Belle, might have been for the doctor to admit that he didn't have the answers to her excessive bleeding and that she needed to be referred to a gynecologist. Unfortunately, many doctors try to come across as well-trained commandos looking to seek out the invisible enemy. A brusque and arrogant manner often results in serious oversights.

Morris, Mitchell M.D. et al. Pelvic Radiation with Concurrent Chemotherapy. Compared with Pelvic and Para-aortic Radiation for High-Risk Cervical Cancer. The New England Journal of Medicine. April 15 l999.
This is a critical read for anyone who is experiencing invasive cervical cancer in a more advanced stage. It was this study that launched the concurrent use of chemotherapy (cisplatin) and radiotherapy as the significantly superior treatment protocol for cervical carcinoma. It proved successful, at three stages, over other formats.

Petticrew M. P., Sowden A. J. et al. False-negative results in screening programs; systematic review of impact and implications. Health Technology Assessment 2000. Vol. 4 (5).

Radetsky, Peter. Killing Cancer Naturally. Longevity. March, 1995.
The thrust of this article is to promote the idea that the body's best defense against cancer is an effective immune system. Hardly a novel idea but for the fact that he goes into some detail about gene therapy - something that five years later is still being experimented with. It is written more in a journalistic style but could be used to promote a large number of alternative causes.

Rogers, June. The Cancer STD. Chatelaine Magazine. January 2000. Pages 30, 31.

Thomas, R. et al. Patient Information Materials in Oncology: Are they Needed and do they Work? Clinical Oncology. November, l999.
The authors of this report investigate the various connections between patient information and patient well being. It is their opinion that specialists and physicians are quick to dispense treatment without making the effort to explain things more thoroughly to the patient. Where the information necessary for better informed choices is lacking, the individual patient will usually turn to more uncontrolled and unconventional sources. It has been our experience that the information available came only as we persisted in digging for it. We've noticed that Belle received some very rudimentary briefing as to the nature of her illness and required treatment. The doctors told us what to do and we did it without question. Only afterwards, did we discover some major gaps in the screening process that went on prior to the treatment. Nobody came to us and discussed the nature of Belle's Pap smears either in terms of what they meant or what the testing criteria were. All this was obtained by dint of persistent searching for answers. This is a great article to read in the sense that it lays out quite clearly where one can go to obtain useful answers if conventional sources fail.

Rose, Peter et al. Concurrent Cisplatin-Based Chemotherapy and Radiotherapy for Locally Advanced Cervical Cancer. The New England Journal of Medicine. April 15, l999.
Reading this article is critical to any understanding as to where conventional treatment is going in cervical cancer. The rates of survival, as a result of this treatment, are nothing short of phenomenal. We partially attribute Belle's survival to taking this course of combined radiation, chemotherapy and surgery.

Schneider, Diana L. et al. Cervicography Screening for Cervical Cancer Among 8460 Women in a High-Risk Population. American Journal of Obstetrics and Gynecology. Vol. 180. Number 2, Part 1. Pages 290-297.

This article takes a very detailed look at other adjunctive methods of cervical screening other than the Pap smear test. The cervigram, or intense review of the cervix, proved to be more effective than the Pap smear in detecting advanced and high-grade cervical lesions. A very effective article, which proves that the Pap smear has severe restrictions and that doctors need to investigate further whenever there are suspicious circumstances.

Thompson, Donald W. Adequate Pap Smears. (A Guide for Sampling Techniques in Screening for Abnormalities of the Uterine Cervix) Laboratory Proficiency Testing Program. Toronto, l996.

Cancer Care of Ontario has made available to doctors and patients a brilliant guide on the effective use and interpretation of the Pap smear. There is nothing to equal it in respect of defining the essential requirements for sound sampling and evaluating of smear samples. It is well laid out in language that anyone can understand.

What is a Pap Smear? American Society for Cytotechnology, asct.com/papsmear.html

We found this on-line brief to be very helpful in explaining how the Pap smear test is conducted and what it is intended to perform.